# The Journey through School

# for Children with Cystic Fibrosis

## An Interpretative Phenomenological Analysis

## Breda T. Cotter

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**Faculty & School**

**Humanities and Social Sciences**

**School of Education, Communication and Language Sciences**

**Supervisor**

Professor Liz Todd

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# Dedication

To the memory of my children's grandparents

Mr. Thomas and Mrs. Maire O'Sullivan
Mr. Martin and Mrs. Brigid Cotter

and my sisters
Mary, Eileen and Rita

# Declaration

**Newcastle University**

**School of Education, Communication and Language Sciences**

I certify that all the material in this thesis, which is not my own work, has been identified and that no material is included which has been submitted for any other award or qualification.

Name:     Breda T. Cotter

Signature:     _____

Date:     <u>02 June 2016</u>

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# Abstract

This study set out to explore the experiences of children making their way through school with a diagnosis of Cystic Fibrosis. Cystic Fibrosis is a chronic illness which requires a rigorous treatment regimen and for which there is no cure. It is a recessively inherited disorder which affects multiple organ systems and involves a life expectancy of approximately 40 years. It is the most common life-threatening disorder in the Caucasian race (Wennstrom et al., 2011) and the incidence in Ireland is the world's highest (Farrell, 2008).

The aim of the study was to explore identity construction among these children with a view to establishing whether or not they consider themselves to be disabled and to have a disability. This involved accessing their self-theories in relation to a series of issues, the main focus being each child's fundamental sense of self. Such a focus was considered an appropriate goal in view of the fact that learning who one is and where one fits into the world is a core preoccupation among school-age children (Erikson, 1968, 1982). In addition, the construct of identity has particular relevance in the context of a chronic illness.

Issues relating to identity and to disability were ascertained by drawing on the relevant literatures in psychology and sociology.

Given that the focus was on the children's life-worlds, the methodology chosen for this study was Interpretative Phenomenological Analysis. Using a set of questions devised on foot of the literature review and covering five domains of enquiry, four children, recruited through the Cystic Fibrosis Association of Ireland and living in different parts of the country, comprised the research sample. Analysis of their responses revealed that the identity construction process is complex and that the issue of disability remains an empirical question requiring additional investigation.

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# Chapter 1. Introduction

## 1.1   Introduction

It is often said that one's school years are the best years of one's life.  Such sentiments conjure up images of carefree days spent discovering new things and developing new skills in the company of friends who are simultaneously sharing these exciting experiences.  The accepted wisdom is that this special time in the lives of children is essentially a preparatory stage on the pathway towards adulthood and independence.  For the majority, this perception holds true.  However, for a small but growing number of children school does not represent an untroubled time among peers having similar experiences.  Moreover, it may not be entirely appropriate to regard it as preparation for adulthood and independent living.  These children are ill, chronically ill.  Their school days and years are not really comparable to those of healthy children.  In fact, very little is known about their route through school because in many instances it is their fight for life itself which has been the focus of attention among those closest to them and those researching their case histories.  The present study represents my attempt to shed some light on the journey through school for one category of chronically ill children: those with Cystic Fibrosis (CF).

## 1.2   Aim

This study set out to explore the experiences of children making their way through school with a diagnosis of CF.  CF is a chronic illness which requires a rigorous treatment regimen but for which there is no cure.  The focus was on the subjective worlds of a small number of such children in the period of adolescence and at critical transitional points in their schooling.  The aim was to explore the identity construction of these children with a view to establishing whether or not they consider themselves to be disabled and to have a disability.  While this necessarily involved accessing their self-theories in relation to a series of issues, the main focus was on each child's fundamental sense of self, an appropriate goal in view of the fact that learning who one is and where one fits into the world is a core preoccupation among school-age children (Erikson, 1968, 1982).  In addition, the construct of identity, 'most often addressed during the adolescent and emerging adult years' (Vignoles, Schwartz and Luyckz, 2011, p. 10), has particular relevance

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in the context of a chronic illness. The overall objective was to generate increased understanding of school-going children having CF and of the factors likely to contribute to their well-being.

## 1.3    Thesis Overview

This research report is presented over six chapters, each of which focuses on a specific aspect of content.

The current chapter introduces my study, addressing its aims, context, rationale and origins before setting out its distinctive contribution in the area of CF research. It offers short introductions to the world view underpinning this research, to reflexivity and also to bracketing.

The Literature Review chapter provides a brief introduction to CF, a review of the psychological literature relating to chronic illness, an overview of the sociological literature on disability and relevant research on the issue of identity.

The Methodology chapter describes my research questions and the methods I used to select participants, generate and analyse data. It also deals with relevant ethical issues.

The Findings - Presentation chapter presents my findings from the interviews with the children. These findings are summarised in a series of tables and described in terms of the themes discovered in the children's talk.

The Findings - Discussion chapter presents my analysis of my findings, discussing them with reference to my research questions and to the research literature.

The Conclusions chapter includes a summary of the aforementioned findings, my reflections on my methodology, some suggestions regarding the implications of this study for psychologists working in education and some recommendations in relation to future research in this area.

The report concludes with a list of References and of Appendices.

## 1.4 Context

The incidence of CF in Ireland 'is the world's highest at 1: 1353' (Farrell, 2007, p. 557). Ireland also has the world's highest CF carrier rate with 1 in 19 individuals classed as 'carriers' of the altered gene which causes this condition (Cystic Fibrosis Ireland (CFI), 2014). Such prevalence rates are nearly four times those of other European Union (EU) countries and of the United States of America (USA), (Java Clinical, 2012). The most up-to-date figures regarding the number of Irish children with a diagnosis of CF are those published by the Cystic Fibrosis Registry of Ireland (CFRI) in its 2012 Annual Report. The registry represented '92.7% of persons with CF (PWCF) known to be alive on the 31st of December 2012', i.e. 1,140 individuals (CFRI 2012 Annual Report, p. 1). Table 1.1 below presents some of the relevant data from that report.

| CF persons registered | 2008 | 2009 | 2010 | 2011 | 2012 |
|---|---|---|---|---|---|
| Children (< 18 years) | 496 | 496 | 494 | 516 | 545 |
| Median age (years) | 9.5 | 9.9 | 10.2 | 9.9 | 9.6 |

**Table 1.1.** Registered Irish Children with a diagnosis of CF (PWCF).
*(Source: CFRI 2012 Annual Report, p. 1)*

This table shows that between 2008 and 2010, the number of children (<18 years of age) with CF was largely unchanged, but consecutive increases have been noted in 2011 and 2012. Given that Cavan Cystic Fibrosis (2014) states that approximately 35 - 40 children are born with CF each year and that 'just over two-thirds of PWCF on the registry in 2012 (1,140) … [and] … 70.5% of < 18s … were diagnosed before the age of one' (CFRI 2012 Annual Report, p. 5) it is likely that the current number of children with a diagnosis is in excess of 545.

The outlook, in medical terms, for these children is difficult to predict, however. The fact is that Ireland has 'a high CFTR mutation prevalence and consanguinity' (Farrell, 2007, p. 559), i.e., some of the most severe strains of CF (CFI, 2014). The numbers surviving beyond childhood may be estimated by looking at the CFRI 2012 Annual Report in relation to PWCF who were > 18 years. Table 1.2 below presents some of the relevant data from that report.

| CF persons registered | 2008 | 2009 | 2010 | 2011 | 2012 |
|---|---|---|---|---|---|
| Adults (> 18 years) | 508 | 531 | 550 | 558 | 595 |
| Median age (years) | 25.5 | 26.0 | 26.6 | 27.2 | 27.9 |

**Table 1.2**. Registered Adults with a diagnosis of CF (PWCF).
*(Source: CFRI 2012 Annual Report, p. 1)*

This table shows that the number of PWCF who were >18 years continued to increase on an annual basis between 2008 and 2012. Indeed, in 2012 there were 37 more adults attending Specialist CF Centres than in 2011. It is likely, therefore, that the current number of adults in Ireland with a diagnosis of CF is in excess of 595. In 2012, the median age of adults was 27.9 years. This compares well with the predictions advanced by other significant parties, e.g., that the median age of survival for persons with CF in Ireland is in the early and mid-30s (CFI, 2014); that approximately half of all persons with CF can expect to live beyond the age of 38 (Health Service Executive, 2014). The CFRI 2012 statistics relating to deaths in the CF population are presented in Table 1.3 below.

| CF persons registered | 2008 | 2009 | 2010 | 2011 | 2012 |
|---|---|---|---|---|---|
| Deaths | 17 | 17 | 16 | 26 | 18 |
| Median age (years) | 23.5 | 25.6 | 28.1 | 23.5 | 25.2 |

**Table 1.3.**      Deaths of Persons with a diagnosis of CF (PWCF).
                 *(Source: CFRI 2012 Annual Report, p. 1)*

This table shows that 18 deaths were recorded in PWCF registered with the CFRI in 2012. This is similar to the number of deaths reported in other years (with the exception of 2010). The median age at which these 18 individuals died was 25.2 years (range 5 - 42 years).

It is clear from the above figures that the CF population in Ireland continues to increase. Length of life for children, few of whom lived to attend primary school in the 1950s, has extended such that increasingly they may be counted among the school-going populations at primary, secondary and third level institutions (CFI, 2014).

## 1.5    Rationale

This research is important because it focuses on Ireland's most common, life-threatening inherited disease (Cystic Fibrosis Association of Ireland (CFAI), 2014) at a time when a growing number of those affected are having to cope both with the demands of living with it for longer and with the challenge of doing so in an educational environment. The nature of the challenge for children dealing with a chronic illness while accomplishing normal developmental tasks is little known or understood. There appears, however, to be a consensus in the literature that such children are at greater risk than their healthy peers for poorer outcomes across a range of areas, including health and safety, material well-being, mental health and education (Sullivan and

Knutson, 2000; Anderson *et al.,* 2007; Richman, 2008; Allen, 2008; De, Small and Baur, 2008; Emerson, Honey and Llewellyn, 2008; Wray and Radley-Smith, 2010). Given that the number of school-going children with CF continues to increase, not just in Ireland but world-wide, research which aims to enhance understanding of the journey they must undertake is likely to shed light not only on CF-specific issues having a global relevance but also on issues relating to chronic illness generally.

The signficance of the focus on children in the period of adolescence relates to their potential vulnerability, irrespective of health status, due to their particular stage of development. The presence of a chronic illness in adolescence may result in even more complicated and stressful circumstances (Warner and Hauser, 2009), as this stage heralds, among other things, a shift in emphasis on the part of such children from issues relating to self-esteem, the motive to succeed and peer group interactions, to one which includes 'vacillating between independence and dependence, the ability to intellectualize and rationalize information about their treatments, rebellion, body image changes, and peer acceptance' (Wise, 2002, p. 76).

The current study is also important because of the prominence it accords to the impact of CF on the lives of children. In this regard, it signals a reponse to the call for a move from the more traditional focus on clinical morbidity and mortality rates in such children (Arrington-Sanders *et al.,* 2006) to one which concentrates on the experience of chronic illness. The adoption of a post-Parsonian (i.e. post 'medical-model' approach as initially elucidated by Parsons, 1951, in his theory of the sick role; cf. also Chapter 2, pp. 33 - 36) and broadly interactionist model of illness is particularly appropriate where the aim is to develop an understanding of the effect of the condition on significant aspects of life. That such information not only has the potential 'to guide clinical decisions and to develop care plans' (Rajmil, Perestelo-Pérez and Herdman, 2010, p. 255) but also is crucial in terms of enabling extension of a comprehensive and sensitive approach both to the child and to his/her family (Woodgate, 2000) further enhances the value of this research.

A major strength of this study is, that in attempting to capture the essence of the experience of living with CF for those undertaking the journey through school and to progress understanding of its impact on important elements of their lives, it prioritises the voices of chronically ill children over all others.

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In this regard, while acknowledging the concept that children, generally, are responsible and appropriate informants (Gadermann, Guhn and Zumbo, 2011), it reveals a commitment to the notion that chronically ill children have minds of their own and offer a different and crucial perspective on their lives (Meuleners *et al*., 2002; Foley *et al.,* 2012).

Research which enables such children to convey their thoughts and feelings in respect of their illnesses is not only necessary (Woodgate, 2000) but also valid as they have been found to be effective communicators of such experiences (Sartain, Clarke and Heyman, 2000). Furthermore, they have been found to be skilled interpreters of their worlds, having the ability to understand and make sense of their illnesses (Sartain, Clarke and Heyman, 2000; Griffiths, Schweitzer and Yates, 2011).

### 1.6    Origin of the Study

I qualified as a primary school teacher in Limerick, Ireland in 1975 and began my teaching career in a north Dublin inner city school.  This brought me face to face with children who were gifted learners, who had learning disabilities, who had emotional and behavioural needs and who came from a variety of social, ethnic and family backgrounds.  I became interested in how children learn, in student outcomes, in topics such as motivation, individual difference and the instructional process itself.  I developed a special interest in students who, for whatever reason, did not attend school regularly, a common feature of schools in the area at the time. I became particularly interested in one group of irregular attendees: those suffering from chronic ill health, whether due to deprivation, disadvantage, or an inherited chronic disorder.

Having completed two years of teaching, as required, in order to qualify as a national/primary schoolteacher, I resigned my position and registered as a full-time student with the Psychology Department, University College Dublin.  Following graduation, I returned to teaching and worked in the special education area, before being appointed principal of a large primary school.

In 1995, I was appointed as a psychologist in the Department of Education and Science/Skills (DES), Dublin, eventually becoming Director of the Dublin and Mid-Leinster Region of the National Educational Psychological Service (NEPS).  While this post was very demanding I was

determined, when the opportunity arose, to carry out research in the area of psychology which was my first passion: the life-worlds of children with chronic illnesses.

I choose children born with a diagnosis of CF. This is an inherited condition which affects many organ systems and is the most common life threatening disorder in the Caucasian race (Wennstrom *et al*., 2011). While still a life-shortening and incurable disease, length of life has increased from a median survival age of 7.5 years in1968 (Wennstrom *et al.,* 2011) to the current situation, which suggests 'a median life expectancy of approximately 40 years', (Arrington-Sanders *et al.,* 2006, p. 5). This means that children born with a diagnosis of CF can reasonably expect to complete primary and secondary education, while some have completed third level education.

I also have a more personal interest in CF, which I have referred to in my application for ethical approval. Three of my sisters were diagnosed with CF between 1952 and 1960. Each had died before reaching her fifth birthday, an outcome which was not uncommon at the time. Ireland not only 'has the highest incidence of cystic fibrosis [in the world], but also may have the largest proportion of families with more than one child' suffering from this condition. (CFRI 2005 Annual Report, p. 16).

## 1.7    Distinctive Contribution

In exploring the identity construction of children having a diagnosis of CF, my research will make a distinctive contribution to knowledge in this area. There is currently no information available regarding such children's identifications.

Much of the CF-related research to date has had a medical focus, due to the extensive medical needs of this category of chronically ill children. This has resulted in improved health outcomes for these children and in an increase in the numbers enrolled in schools. Having consulted some parents of school-going children, I know that concerns regarding their educational needs are on the increase. A particular dilemma relates to the issue of disability status and to the need for children seeking educational accommodations to acquire such classification. From my conversations with parents, I understand that adolescents, in particular, frequently have issues in

this regard, preferring not to have an additional label, as they see it, in order to benefit from such resources.

An important question, therefore, is whether children with CF consider themselves to be disabled and to have a disability.  This question has not been addressed in the disability literature.  My research has been designed to fill this gap in knowledge and to do so in a sensitive, respectful manner. My findings will be of interest and value not only to the CF community, but also to the education and medical communities.

## 1.8    My Place in the Research

Having spent many years working with children of all ages I have come to believe that knowledge is built or constructed by learners, not supplied by teachers (Papert and Harel, 1991) and not discovered by the mind (Schwandt, 2003).  Students construct their individual meaning systems by building on their previous knowledge and experience. New ideas / experiences are matched against existing knowledge and the learner constructs new or adapted rules to make sense of the world.  Thus, students come to learning already possessing their own constructs of the world.

Extrapolating from such a set of convictions, I have also come to believe that each of us constructs his or her own version of reality, a standpoint which suits a constructivist epistemology most comfortably (Gray, 2006).  This unique construction process is based on one's past experiences, personal views and cultural background.  Thus, no two persons' realities will be the same; everyone's view of the world will be different.  However, while holding a constructivist epistemological perspective which allows for multiple representations of reality, thereby emphasising the complexity of the real world, I nevertheless reject relativism and the notion that people can never hope to understand each other due to their differing experiences and cultures: we can always hope to learn from each other's experiences and to understand each other.

A complicating factor for me, nonetheless, is the fallibility of our perceptions.  In this regard, I am more in tune with those constructivists who, in post-positivist fashion, believe not only that we each construct our view of the world based on our perceptions of it, but also that such

perceptions are flawed and therefore ultimately incapable of enabling us to see the world perfectly as it really is. Such constructivists are termed critical realists: they are critical of one's ability to know reality with certainty. In critical realism, all observation has error and is theory-laden; all observers are inherently biased due to their cultural experiences, world views, etc. People's constructions of the world must, therefore, be imperfect.

This is not to deny that there is a real world out there which exists independently of our knowledge of it; it is just that such an assumption cannot be conclusively proved or disproved. Thus, there is no absolute knowledge, only one's interpretation of it. Accordingly, our constructs of the world are based both on our previous experiences and on our interpretation of the information being presented to us. As Sayer puts it: 'Meaning has to be understood, it cannot be measured or counted, and hence there is always an interpretative or hermeneutic element in social science' (Sayer, 2000, p.17). That all explanations are necessarily fundamentally interpretivist in character is accepted by critical realists. The challenge, however, is not just to provide the 'best' current interpretation but also to include the researcher's understanding of the subjects' understandings, i.e. to face the problem of the double hermeneutic. This applies, in particular, when analysing respondent - based data (Woodside, Pattinson and Miller, 2005), as I am attempting to do in this study.

The fact that I am also attempting to get as close as possible to the personal experiences of my participants, in effect to their individual lifeworlds, suggests an additional phenomenological element in relation to my research. This arises not only because the interpretation of people's meaning-making activities is central to phenomenological inquiry in psychology but also because phenomenology aims to remain as faithful as possible to the phenomenon, that is to the thing itself, the thing being lived experience. In phenomenology, the objective is 'to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place. From this rich contextual example of the phenomenon as lived by the participant, phenomenological analysis attempts to discern the psychological essence of the phenomenon. In other words, phenomenology seeks the psychological meanings that constitute the phenomenon through investigating and analysing lived examples of the phenomenon within the context of the participants' lives' (Giorgi and Giorgi, 2008, p. 28). Thus phenomenology deals with experiences and with meanings.

## 1.9 Reflexivity

Reflexivity is a qualitative research strategy which addresses the subjectivity of the researcher in relation to people and events encountered during the research process. It also addresses the subjective nature of the research and it enhances the quality of research through its ability to extend our understanding of how our own positions and interests affect all stages of the research process (Primeau, 2003).

I was conscious of the history of CF in my own family and consequently of my personal interest in this subject. I, therefore, reflected deeply on my stance in relation to the topic I was researching. I attempted to identify the ways in which my standpoint might shape the research process and the findings. While I saw the research as a joint product of the researcher and the researched, I was conscious, as Malterud (2001) states, that: 'A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions' (p. 483). However, he also states that: 'Preconceptions are not the same as bias, unless the researcher fails to mention them' (Malterud, 2001, p. 484).

Reflexivity requires an awareness on my part of my contribution to the construction of meanings throughout the research process. I acknowledged the difficulty of remaining an 'outsider' in a subject matter so close to me personally, while conducting the research, but I strove to explore the ways in which my involvement with this study influenced, acted upon and informed the research.

Reflexivity entailed my being aware of my own effect on the process and on the outcomes of research, based on the premise that 'knowledge cannot be separated from the knower' (Steedman, 1991, p. 53).

Willig (2013) writes that there are two types of reflexivity: personal reflexivity and epistemological reflexivity: '*Personal reflexivity* involves reflecting upon the ways in which our own values, experiences, interests, beliefs, political commitments, wider aims in life and social identities have shaped the research' (p. 10). Personal reflexivity required that I reflect on my

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reason for choosing this topic in the first place and on how the exercise might change me as a person and as a researcher.

'*Epistemological reflexivity* requires us to engage with questions such as: How has the research question defined and limited what can be 'found'? How have the design of the study and the method of analysis 'constructed' the data and the findings? How could the research question have been investigated differently? To what extent would this have given rise to a different understanding of the phenomenon under investigation'? (Willig, 2013, p. 10). Epistemological reflexivity encouraged me to reflect on the assumptions that I had made in the course of the research; it also helped me to think about the implications of such assumptions for my research and for my findings.

As a result I engaged in personal, epistemological and methodological reflexivity throughout the period of my research, through reflection upon my previously held assumptions about the world and about the knowledge created as a result of this research.

## 1.10 Bracketing

All the measures adopted by me were designed to ensure that the findings would be as close as possible to the participants' meanings. I had to decide how much influence I could bring to bear throughout the research process.

Bracketing is a methodological device in phenomenological inquiry which required the deliberate putting aside, on my part, of what I already knew about CF, because of my family history, prior to and during the phenomenological investigation**.** Bracketing is the holding in abeyance of those elements which define the limits of an experience and is a means of demonstrating the validity of the data collection and analysis process (Ahern, 1999)**.** Every effort was made by me to put aside my knowledge, beliefs, values and experiences of CF in order to accurately describe the participants' life experiences. However, in the phenomenological hermeneutic approach, it is acknowledged that pre-understanding cannot be eliminated or completely bracketed (Koch, 1995).

Understanding the participants' lived experiences marks phenomenology as based on Husserl's philosophical work. Freeman (2011) asserted that understanding cannot be conceived as a fixing of meaning but rather how the meaning is generated and transformed. In order to discover meanings in the data, the researcher needs an attitude open enough to let unexpected meanings emerge (Giorgi, 2011). The concept of bracketing is well-suited in research which aims to explore human experience.

The inherent human factors and the ability to be aware of the researcher's preconceptions are the key attributes which can affect bracketing. I was the primary instrument for data collection and analysis in this qualitative research. Crotty (1996) pointed out that it is not humanly possible for qualitative researchers to be totally objective. If the researcher is unaware of his/her own preconceptions and beliefs, it is impossible for him/her to put these issues aside. Therefore, the ability to be aware of one's own values, interests, perceptions and thoughts becomes a prerequisite before one can set aside the things that influence the research process.

Before deciding on the research paradigm, I had to confirm to myself that I could put aside my own knowledge and adopt this attitude throughout my research. I asked myself the question: 'Can I equip myself to adopt an attitude of conscious ignorance about the issue under investigation'?

In attempting to answer this question, I revisited my own experience of and attitude towards CF, the origins and objectives of the study and my place in the research. I also re-examined the insights of Steedman (1991), Malterud (2001), Primeau (2003) and Willig (2008) in relation to the issue of reflexivity. Having engaged in this exercise, I was clearer about those matters having the potential to influence the research process and which needed to be set aside by me throughout same. Accordingly, I made every effort to 'equip myself to adopt an attitude of conscious ignorance about the issue under investigation' and to ensure that I could answer the question in the affirmative. At this point, I returned to the principles inherent in phenomenological inquiry and decided that the latter was my methodology of choice. Finally, having started the research journey, I asked myself about the kind of new information which might be generated on foot of the research. I found that I could not answer this question readily, which meant that I was open-minded.

# Chapter 2. Literature Review

## 2.1   Introduction

In this chapter I provide a brief introducton to CF outlining its main features and effects.  I then consider research which has specifically examined the psychological impact of chronic illness, including CF, on the lives of school-going children.  This is followed by an overview of aspects of the sociological literature on disability having relevance for this study.  Finally, I consider the issue of identity, exploring the relationship between this construct and models of disability generally.

## 2.2   Cystic Fibrosis

### 2.2.1   What Is CF?

CF is a chronic illness which is most often diagnosed in infancy or early childhood. According to the Cystic Fibrosis Foundation (CFF) more than 75% of the circa 1,000 new cases diagnosed in the USA each year are diagnosed by age 2 (CFF, 2014).  A number of cases are also identified in adults.  An analysis of the CFF patient registry data for 2001 indicated that 9.9% (n = 100) of all new diagnoses in the USA that year had been confirmed in those aged 18 or older, the mean age being 34 years.  Furthermore, the incidence of delayed diagnosis is expected to increase.  In this regard, according to Widerman (2003), a paper presented at the World Health Organisation (WHO) Genetic Epidemiology Meeting in Italy, in 2002, 'pointed out that the identification of over 1000 mutations and the wider availability of genetic testing now make possible the diagnosis in those who have atypical symptoms and/or achieve negative, or equivocal, sweat test results' (p. 97). Thus, CF is no longer regarded as a childhood illness but as one which affects both adults and children.

### 2.2.2   Prevalence of CF

CF, as noted above, is the most frequent hereditary disease among white people (Goldbeck and Schmitz, 2001; Wennstrom *et al.,* 2011).  It affects approximately 70,000 people worldwide (CFF, 2014).  That said, the incidence varies across the globe (WHO, 2014). For example,

although severely underdiagnosed in Asia, existing evidence indicates that the prevalence of CF is rare. In the USA, however, the incidence is reported to be 1 in every 3,500 births (WHO, 2014). Hence the estimate by the CFF that approximately 30,000 children and adults in that continent have CF.

As regards the EU, it would appear that 1 in 2000-3000 new borns is found to be affected by CF (WHO, 2014). In this context, a study by Farrell (2008), which combined a variety of methods to determine the prevalence of CF in 27 EU countries, revealed a mean prevalence of 0.737/10,000 in the EU. The range of CF prevalence was from 0.104 in Latvia to 2.98 in Ireland (per 10,000). Thus, Farrell declared 'that only the Republic of Ireland is an outlier' (p. 451). Interestingly, our nearest neighbour, the United Kingdom (UK) was found to have 'the next highest prevalence at 1.37 per 10,000' and also to have 'one of the highest incidence values at 1:2381' (Farrell, 2008, p. 452).

### 2.2.3 Causes and Effects

CF is a recessively inherited disorder which is caused by mutation of a single gene. As already stated, there are over 1000 different mutations (cf. Widerman, 2003) and a variety of levels of symptom severity both between individuals and across the lifespan (Small and Rhodes, 2000). It is a complex disease, which affects multiple organ systems. The body organs mainly affected are the lungs and the pancreas. CF causes glands in the body to produce abnormally thick and sticky mucus secretions, which block or clog the bronchial airways and the digestive system (MedicineNet, 2014). If left untreated, the mucus in the airways of the lungs builds up and becomes the site of recurrent bacterial infections that lead to progressive damage and ultimately respiratory failure. 'Much of the morbidity and mortality associated with cystic fibrosis is due to pulmonary disease' (Arrington-Sanders *et al.,* 2006, p. 5). The mucus also obstructs the pancreas and blocks the passage of digestive enzymes to the small intestine which untreated leads to mal-absorption, vitamin deficiency, weight loss and ultimately severe malnutrition. However, while respiratory and gastrointestinal problems are particularly frequent in CF, patients sometimes also develop reproductive problems, diabetes mellitus, chronic liver problems (Wennstrom *et al.,* 2011) and bone disease (MedicineNet, 2014).

### 2.2.4  Treatment

Being a multisystem disease, CF demands adherence to a treatment regimen which has been labeled by one commentator as 'the chronic burden of care' (Ievers and Drotar, 1996, p. 49). This care consists of a strict, complex and time-consuming schedule of therapy and medication which must be complied with, on a daily basis, regardless of (current) clinical status and symptoms, if disease progression is to be delayed.  In this regard, a key feature of the daily routine is the physiotherapy regime.  This is designed to facilitate the removal of mucus from the airways and thus to aid respiratory function.  Most patients undergo twice daily sessions of chest physiotherapy in order to expectorate mucus from their lungs.  They are also exposed to an extensive array of medications.  These include antibiotics taken orally or inhaled to both prevent and treat infections. In cases of acute infection antibiotics are delivered intravenously.  Adult patients often self-administer intravenous antibiotics.  In addition, 'pancreatic enzyme capsules … [must be] … taken before the consumption of any food to replace those that are absent from the affected digestive system' (Jessup and Parkinson, 2010, p. 352).  However, many people also take vitamin supplements to counter the problems of mal-absorption.  A high calorie diet is essential, as well, to ensure adequate nutrition (Small & Rhodes, 2000).

Disease progression usually implies more frequent hospital visits and an increase in the complexity and intensity of the treatment regime: nocturnal nasogastric or gastrostomy feeds may be introduced to maintain body weight; aggressive antibiotic treatments and the use of oxygen will become increasingly necessary as breathing becomes more difficult.

### 2.2.5  Treatment Effects

This arduous treatment regimen, estimated to require a minimum of one hour to complete each day, has, nevertheless, been directly linked with remarkably better health outcomes for people with CF. More specifically, early diagnosis, centralized care, improved antibiotics and finer adjusted nutrition, together with a move to active physiotherapy, have led to a dramatic increase in life expectancy generally.

Enhanced survival means that people with a diagnosis of CF must adapt to and deal with the exigencies of living with this condition for longer (Foster *et al.,* 2001).  It also denotes additional

challenges and concerns for the CF community, both professional and lay, in that the aforementioned 'chronic burden of care' (Ievers & Drotar, 1996, p. 49) now extends to an adolescent and adult population.  In this context, Arrington-Sanders *et al.,* (2006) report that researchers no longer focus simply on the medical features of CF.  Instead, the emphasis is shifting towards exploration and understanding of the effects of the disease and of its treatment on important aspects of the lives of children, adolescents and adults with the diagnosis.  In this way, provision of appropriate medical, psychosocial, educational and vocational services may become possible for a unique cohort of people attempting to go where few with similar life stories have gone before.

## 2.3  Chronic Illness

### 2.3.1  Definitions

The definition of health provided by the WHO in 1948 and not amended in the intervening years, marks it out as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.  This serves to highlight the all-embracing nature of the concept. It also helps to underscore the wide-ranging effects of disease.  In this context, it has been reported that in the case of rare diseases 'the majority lead to physical, emotional and/or psychosocial limitations with a wide range of disabilities' (Rajmil, Perestelo-Pérez and Herdman, 2010, p. 254).  Together with CF, those diseases termed 'rare' include such debilitating conditions as cerebral palsy, congenital cardiac diseases, bleeding disorders, digestive disorders, neuromuscular disorders and spine deformities.  Their chronic status stems from the fact that each 'lasts for a substantial period of time or ... has sequelae that are debilitating for a long period of time' (Perrin, 1985, p. 2) i.e., they interfere with daily life over a sustained period of time (Pless and Pinkerton, 1975), possibly lead to hospitalization for in excess of four weeks per year and have the potential both to worsen and to be fatal (Boice, 1998; Schwean & Saklofske, 1999), since while they may be treated, they cannot be cured.   In contemporary society, due to their increasingly protracted nature, much of this treatment and of the management of chronic conditions generally is carried out by family members and/or by community caregivers, including, in some countries, school personnel.

## 2.3.2 *Prevalence Rates*

Of considerable significance is the fact that, as already indicated in the case of CF, prevalence rates for conditions such as those named above have increased in recent decades. In addition, it now appears that co-morbidity rates have also increased: 10% - 20% of children suffer from one or more chronic illnesses (Williams, Holmbeck and Greenley, 2002; van der Lee *et al.,* 2007). Such developments have been attributed to a number of factors: advances in medical technology which have led to improved detection, treatment and survival rates – for example in relation to childhood cancers; increases in survival rates of premature infants – who develop more neurological, respiratory and cognitive dysfunctions than healthy birth weight babies; the emergence of new childhood diagnoses - such as pediatric HIV/AIDS (Thompson and Gustafson, 1996). With continued medical advances resulting in reductions in the risks of life-threatening complications of serious health conditions and, consequently, increases in life expectancy among sufferers, rates of chronic disease in children will inevitably continue to rise. In these circumstances, I believe that many conditions currently termed 'rare' may not retain such a designation in the not too distant future.

## 2.4   Impact of Chronic Illness/CF

In attempting to research the impact of CF, specifically, on the lives of those with the diagnosis I was struck by the fact that much of the evidence-based information relating to them and to their families is often just about extractable from studies dealing generically with people having chronic illnesses. Alternatively, CF is frequently considered in conjunction with certain other chronic conditions, such as asthma, despite the fact that such conditions may have dissimilar presentation, course, consequences and prevalence rates. Issues of comparison and of generalization are particularly problematic as the subjects in CF research are invariably young, identification of the condition in adults being relatively recent and much of the evidence is based on parents' and or carers' perceptions of its effect on children. However, all such research contributes towards the knowledge base in respect of CF and of chronic illness generally. Accordingly, this review, while focusing on CF, will also include relevant material from research dealing with other chronic diseases.

With respect to the issue of identity, a topic which has received considerable attention from the research community since Erikson's seminal work in this area (1950, 1968, 1982) much of the literature deals with the array of structures, mechanisms and processes which has emerged in various personal/social perspectives on the phenomenon; there is also a considerable focus on issues such as gender, sexuality, class and culture.  However, this literature has minimal relevance in the current context; moreover, since it tends, in the main, to reflect the voices of able-bodied adults it has not been included in this review.  What has been included, due to its unquestionable relevance in the context of identity and illness/CF, is the literature relating to same and also to identity and health/well-being.  The matter of identity and disability, a key element of this study, will be dealt with separately, at the end of this chapter (see pp. 36 - 39).

Given the various literatures requiring consideration, as outlined and the particular objectives of this study, I decided to create an integrative framework within which to present my review.  This framework emerged following analysis of the themes arising in the review and the generation of a set of constructs to capture each in turn.  Thus, the literatures reflecting a particular theme (e.g. 'sense of self') are reviewed under a particular, corresponding construct (e.g. 'being').  In this way, the thematic analysis, which essentially revealed five domains of enquiry (see Methodology chapter, pp. 43 - 45), resulted in the development of five constructs.  These constructs formed the integrative framework around which the literature review was organized.

The link between each domain and construct is presented in Table 2.1 below.

| Domain of Enquiry | Construct |
|---|---|
| The impact of CF on the children's sense of self | Being |
| What CF means to the children | Needing |
| The impact of CF on the children's sense of life in general | Coping |
| The impact of CF on the children's sense of the future | Hoping |
| The impact of CF on the children's school life | Schooling |

**Table 2.1.**      Domains of Enquiry and Corresponding Constructs

The additional link between these constructs and the interview questions was accomplished by drawing on the domains of enquiry, as detailed in the Methodology chapter, pp. 50 - 51.

## 2.4.1 *Being*

The literature in this area concerns the effect that having a chronic illness, including CF, has on people's fundamental sense of self. That this is a critical factor in the experience of illness has been readily acknowledged since Charmaz's (1983) seminal study which highlighted the 'loss of self' that accompanies chronic illness. The significance of this study for me also relates to the fact that it involved qualitative investigation of a relatively large number of people (57) having a variety of diagnoses at a time when the predominant practice was to use quantitative measures of the illness experience, including that of 'sense of self' (Woodgate, 2000). Providing subjects' accounts of their fractured self-images, due to serious illness, adds powerfully to the body of evidence in quantitative studies of this topic. However, it must be pointed out that the bulk of this material relates to people who enjoyed a period of good health before the onset of their illness, unlike those having CF. Essentially, the accumulated evidence suggests that a number of factors potentially impact negatively on the chronically ill person's sense of self. These include:

- appearance changes, e.g. loss of hair in cancer patients, reduced stature in adolescents with CF;
- restrictions on everyday life, e.g. undergoing dialysis at regular intervals for people with kidney problems, daily physiotherapy for adolescents with CF;
- isolation, e.g. intensive care for transplant patients, segregation of adolescents with CF;
- burdening others, e.g. physical assistance for the incapacitated, adherence to a demanding regime for the families of adolescents with CF;
- lack of understanding, e.g. fear of contagion in relation to people with chronic dermatological conditions, lack of knowledge in relation to the consequences for adolescents of having CF.

However, the research also suggests that self-perceptions vary as people's health status changes. This may signal positive variation where the individual's health is improving but it may also reflect either reconciliation or resignation consistent with a deteriorating health condition (Charmaz, 1995). Indeed, there is much evidence to suggest a link between chronic illness and anxiety and depression (McKay and Storch, 2011), the 'presence of a medical condition [appearing] to in fact increase the likelihood of experiencing a mental health problem' (Farrell *et al.,* 2011, p. 479). That said, it would appear that 'Research from around the world suggests that

people with CF, despite the burdens that the disease and its treatments impose on them, are psychologically well-adjusted and generally report a good HRQoL [health-related quality of life] on many domains of generic and CF-specific measures' (Abbott, 2009, p. 32). In this regard, it is noteworthy that adolescents with CF are less likely than the general population to have a recognized psychiatric disorder.

Nevertheless, there appears to be a consensus in the literature that the chronically ill, inclusive of those with CF, have a sense that the self is different. Furthermore, it would appear that such persons tend to locate the 'difference' in themselves (Williams, Gannon and Soon, 2011). This may be attributable, primarily, to the fact of having a diagnosis, a label. As Alsaker, Bongaardt and Josephsson (2009) have pointed out in relation to women with chronic rheumatoid conditions (CRCs) 'Persons living with CRC might not need or want to be different, but being diagnosed with a condition like CRC imposes a difference' (p. 1154). However, the literature has also revealed that having a diagnosis does not necessarily imply that the individual considers him/herself to be ill. Rather, 'this equivalence must be established and internalized by the patient' (Huyard, 2008, p. 538). That same has the potential to be a rather lengthy process is aptly illustrated by the woman, diagnosed at 14 years of age with Wilson's disease, who remarked towards the end of her illness, approximately 22 years later: 'Now, I really know that I did have Wilson's disease' (Walsh and Dixon, 1986, p. 847). Hence, perhaps, the sense of confusion among many chronically ill people in relation to their status: they feel that they are in limbo, not ordinary and not ill, except when ill. This is particularly true of young people with CF whose bodies can be reliable for long periods, allowing them to lead relatively stable lives until the whistle-blowing incident occurs. As Tim, in Jessup and Parkinson (2010), puts it: 'I remember thinking: "Oh, shit. Yes, I am sick"' (p. 359).

An additional complicating factor, in the context of their emerging concepts of self, concerns the tendency among the chronically ill to frame identity questions in relation to the healthy and able; accordingly, their judgements of themselves tend to be made in line with conventional yardsticks and to yield unsatisfactory outcomes (Charmaz, 1983). However, even though 'chronic illness seems to foster greater dependence on others for self-definition and value' (Charmaz, 1983, pp. 190-191) and to generate feelings of inadequacy in respect of normative standards, a key theme in the literature in this area relates to the unwillingness, on the part of this cohort of people, to be regarded as different by others; moreover, not wanting to be treated differently appears to mean

wanting to be treated as 'normal' people (despite the shortcomings they perceive themselves to possess in the relational context).

A major limitation with regard to this literature, though, is the lack of consistency in relation to the definition of 'normal', of what it means 'to be normal' and, therefore, of 'the normalization process' so frequently referred to in studies of chronic illness. In addition, there is a lack of research into the potential link between issues relating to 'normality' and the age of diagnosis of the individual. From my reading of the available literature, however, it would appear that the age at which one is diagnosed may have a bearing on one's concept of normality. For example, in the case of an individual whose diagnosis occurs some years into his/her life and whose illness therefore constitutes a biographical disruption, leading to a new life-phase, it would appear that normality may refer to his/her way of life before the diagnosis. In such cases, it is held, furthermore, that one's sense of self, or identity, as established prior to the diagnosis may impact one's recovery and return to a 'normal' life. On the other hand, and importantly from the point of view of the current study, in the case of those whose diagnoses occur in infancy or early childhood, to live with one's illness is obligatory from the outset. In such circumstances, as Jessup and Parkinson (2010) put it in relation to CF: 'there are no before and after images' (p. 357). However, what 'normal' means in these situations is unlikely to equate with its meaning for those receiving late diagnoses. Moreover, whether and to what extent such illnesses impact a sense of self is also unclear given the dearth of research in this area.

### 2.4.2   Needing

The literature in this area concerns the effect that having a chronic illness, including CF, has on people's well-being. Much of the evidence in relation to this concept has come from studies involving healthy and able adults. Some studies have involved children. However, where such studies included children with disabilities they would have been 'in a minority and not examined separately' (Foley *et al.,* 2012, p. 377). Thus research into the meaning of well-being among ill children is sparse (Llewellyn and Leonard 2010) and the potential that such investigation could yield, in respect of positive outcomes for already heavily challenged individuals, is effectively untapped. What the literature does, nevertheless, reveal is that the definition of well-being itself is highly variable, irrespective of the population involved. In this regard, studies point to the existence of at least two distinct philosophies regarding its conceptualization: well-being as

hedonic happiness and well-being as involving the actualization of human potentials (La Guardia, 2009; Waterman, 2011). Well-being in the opinion of children, specifically, appears to vary according to, at the very least, the following factors: age, life phase, gender, ethnicity, socio-economic status, geographical location, ability and disability (Frønes 2007; Fattore, Mason and Watson, 2009; Hanafin and Brooks 2009; Australian Institute of Health and Welfare, 2009b). Accordingly, well-being in the opinion of children, generally, is a rather complex phenomenon. Would the presence of a chronic illness add to or detract from this complexity? Given the large gap in the literature, currently, in relation to the perspectives of ill children on this subject (Foley *et al.,* 2012), it is difficult to provide a definitive answer.

In light of this complexity as outlined, the current review has aimed for a broad approach to well-being and does not subscribe to any particular definition of the concept. That said, there appears to be a consensus in the literature that having a chronic illness leads to a loss of well-being in the general sense of that term: overall quality of life. In this regard, the sources of diminished well-being appear to include frustration of the following in the case of the chronically ill and those having CF.

*Their need for autonomy:* – a basic human need (cf. Deci and Ryan 1985 and 2000, whose Self Determination Theory has 'steadily expanded over the past four decades and ... been applied in various domains, such as education' (Soenens and Vansteenkiste, 2011, p. 382) because it successfully demonstrates both the link between need satisfaction and the construction of a well-integrated identity and the fact that need frustration may hamper identity development).

That having a chronic illness/CF affects people's need to be self-governing is evidenced in the relevant literature, though the term autonomy is frequently used interchangeably with independence and individuality (Soutter, Gilmore and O'Steen, 2011), making distinctions and comparisons between studies somewhat challenging. Nevertheless, a common thread in the literature relating to children and youth with disabilities is the lack of opportunity to make decisions in relation to matters which affect them and the lack of control over their lives (Foley *et al.,* 2012). In addition, being chronically ill has been shown to lead to feelings of powerlessness (e.g., in relation to childhood cancer - Woodgate, 2000; in relation to CF – Jessup and Parkinson, 2010) and of altering between a sense of self as agent and as undergoer (e.g., in relation to paediatric liver transplantation – Wise, 2002; in relation to dialysis – Charmaz, 1983). Such

feelings impact negatively on well-being as when behaviour feels compelled or controlled, as distinct from self-initiated and regulated, it is neither willingly endorsed nor experienced as particularly satisfying (Patrick *et al.,* 2007).

*Their need for competence:* – another basic human need (Deci and Ryan, 1985, 2000). The literature in this area tends to refer to people's need to experience mastery and challenge, a need which 'does not rest on expectations of success but instead relies on the act of simply "doing" or engaging in activity to broaden one's capacities' (La Guardia, 2009, p. 92). However, when written about in terms of efficacy, a further dimension is revealed: the need to *see* oneself as competent and capable of acting on one's world (Vignoles, 2011). In both respects, chronically ill children experience difficulties, though the research in this regard appears to focus, for the most part, on two types of competence: academic and social. In the case of the former, it would appear that many present with learning difficulties and that those having congenital conditions, such as CF, tend to perform relatively less well as a rule due to a variety of factors (cf. Schooling section, pp. 29 - 33; also Koscik *et al.,* 2004; Taras and Potts-Datema, 2005; Wray and Radley-Smith, 2010). The evidence in the case of social competence is also rather stark, though differing conceptualizations necessitate caution in relation to discussion of this construct. Nevertheless, studies involving children and adolescents having chronic kidney disease, renal transplants, congenital heart disease, cardiomyopathy, primary pulmonary hypertension and CF demonstrate deficiencies in social competence ranging from approximately 38% to 75% of the samples in question (Berney-Martinet *et al.,* 2009; Wray and Radley-Smith, 2010). Where the medical condition actually deteriorates, as in the case of CF, developing increased mastery and capacity may be expected to become progressively more elusive, while the potential to perceive oneself as competent and capable may become correspondingly difficult to realize.

*Their need for relatedness* – the third basic psychological need according to Deci and Ryan (1985, 2000). Relatedness refers not only to people's need to belong and to be regarded as significant by others but also to the need to be included and accepted by others (Ryan and Deci, 2000a; Vignoles, 2011). That such needs are frustrated in the case of chronically ill children is clear in the literature in this area. For example, within-family relatedness is repeatedly tested in the case of children having CF. In this regard, the evidence suggests maternal depression, paternal withdrawal and a divorce rate among the parents which is double that of parents dealing with other chronic illnesses and none (Carew, 2001; Jessup and Parkinson, 2010). Indeed,

'frustrations and annoying experiences with siblings' have been raised by children and youth diagnosed with a variety of disabilities as factors which inhibit wellbeing, though some caution is advised in this context due to the dearth of relevant research (Foley *et al.,* 2012, p. 382).  Having a chronic illness/CF also impacts negatively on one's connectedness to friends and peers.  Being taken away from them and losing crucial contact with them is often the hardest part of their illness for many children regardless of their age (Griffiths, Schweitzer and Yates, 2011).  However, the isolation and loneliness they experience often results in their feeling like outsiders, having limited circles of friends and being 'actively excluded by their peers' (Wise, 2002; Williams, Gannon and Soon, 2011, p. 707).  Where chronically ill children have neither a sense of belonging nor of inclusion or acceptance, it is likely that they will not feel that they have significance in the eyes of others and, therefore, not experience well-being.

*Their need for participation* – considered a basic human need by McCaslin (2009), whose co-regulation model of identity has been acknowledged for 'calling attention to ... phenomena that usually have not been addressed by previous theories' (Brophy, 2009, p. 155) and for highlighting the fact that who one is includes what one is and is not willing to do or become, i.e. that one's participation experiences inform one's emergent identity.

The significance of participation for people with disabilities generally has been recognised both by the United Nations (2007) and by the WHO (2001, 2007), though in the case of the latter the term appears to also include activity (Foley *et al.,* 2012).  Having a chronic illness has the potential to seriously limit one's opportunities to participate, to engage in activities, to be involved.  In this regard, children and adolescents tend to highlight being unable to participate in physical activity (Williams, Gannon and Soon, 2011), specifically sporting and recreational activities (Griffiths, Schweitzer and Yates, 2011).  However, they also tend to link same with missed opportunities to feel involved and to play valued roles wherever possible.  Indeed, it would appear that it is missing 'joining in with friends and family and having personally meaningful things to do' which seems to really matter to children and youth with disabilities (Foley *et al*., 2012, p. 380).  Even where such participation can be experienced, though, the uncertainty which accompanies many chronic medical conditions, including CF, tends to result in sporadic as distinct from sustained involvement, a level of engagement which is unlikely to yield copious benefits (Huebner and Mancini, 2003; Denault and Poulin 2009).  In the absence of beneficial participation experiences and consequently of opportunities to engage in well-being

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enhancing activities and to sample the 'fun, [and] freedom from constraints (such as rules and routine)' which accompany such activities (Fattore, Mason and Watson, 2009, p. 67), it is difficult for the chronically ill to foster a sense of well-being.

### 2.4.3   Coping

The literature in this area concerns the effect that having a chronic illness, including CF, has on people's psychological disposition and behaviour. This effect is commonly described as an adjustment and refers to the adaptive process into which people are cast when faced with a positive diagnosis.  The evidence in this regard reveals a rather complex picture, however (Stanton, Revenson and Tennen, 2007).  This arises because of the array of variables having the potential to affect adjustment: the type of medical condition in question, the circumstances surrounding its presentation, the severity of the condition, the age of diagnosis, the prognosis for the individual, the heritability factor, the treatment regimen, the family situation, the level of prior exposure to illness and to the health care system in general.  In addition, given the dearth of evidence generally in relation to chronically ill children, it would appear that the picture in respect of adjustment in children and of what might constitute 'an adequate range of adjustment reactions among children' is particularly unsatisfactory (Woodgate, 2000, p. 217).

Nevertheless, the nature of the adaptive process which appears to apply in the case of children and adolescents is becoming increasingly clear in the literature, especially in that body of work which documents the coping strategies they employ in the effort to deal with their situations.  It must be stated, in this context, that the HRQoL research is also instructive though there 'has been little consensus on how to measure HRQoL in CF at a conceptual or operational level, and there is no "gold standard"' (Abbott, 2009, p. 32).  In general, however, that children and adolescents with CF are psychologically well-adjusted and tend to indicate good levels of HRQoL, as noted above, has been widely reported (Goldbeck and Schmitz, 2001; Abbott and Gee, 2003; Sawyer *et al.,* 2004; Szyndler *et al.,* 2005; Abbott, 2009).  Indeed, that CF patients with end-stage lung disease confirm fewer difficulties, including less anxiety, than others awaiting transplantation, though they may actually be sicker, has also been reported (Burker *et al.,* 2000).  Attempts to explain such outcomes seem to focus on the issue of meaning and to suggest that re-evaluating what is important in life has adaptive benefits in the main (Heine, Proulx and Vohs, 2006) and may be of the essence when faced with traumatic situations.  Children and adolescents with

cancer, for example, demonstrate 'renewed perspectives ... refusing to worry over the little things' (Griffiths, Schweitzer and Yates, 2011, p. 87); the predominant approach in respect of CF appears to be that it is the quality of life, as distinct from the quantity, that matters and being able to endow same with purpose and value (Jessup and Parkinson, 2010).

Notwithstanding such positive findings in the literature in this area, it is also evident that having a chronic illness, including CF, can elicit behaviours which reveal a less clear, albeit strategic, approach. In this regard, those most frequently reported and most relevant in the current context include the following:

*Normalization* - the attempt 'to live life as normally as possible, … a major coping effort [designed] to neutralize illness-related threat' (Nobili *et al.,* 2011, p. S48). Normalization strategies such as glossing over symptoms and minimizing discomfort were identified by Charmaz, as far back as 1983, in relation to chronically ill adults for whom 'failure to live up to the expectations of others' also represented 'failure to live up to their own expectations' (p. 187). That creating a new normal and new meanings of normalcy to replace old, fractured meanings is a common strategy among chronically ill children was reported by Clarke-Steffen in 1993 and 1997. This new normal essentially involves incorporating their daily medical regimens into their lives such that same become routine. In this way, the extraordinary becomes commonplace, they avoid calling attention to themselves and can concentrate on living their lives as normal children (Wise, 2002). However, while such a stance has obvious adaptive benefits and enables these children to reduce feelings of non-normalcy, researchers have also pointed to the dangers inherent in an approach which could lead to a denial of the fundamental implications of their illness. Subjugating themselves to the 'norm' (Williams, Gannon and Soon, 2011, in relation to Epidermolysis Bullosa Simplex) and engaging in a 'flight from the truth' (Jessup and Parkinson, 2010, p. 358, in relation to CF) which effectively involves 'pretending to be someone else for the sake of others' (Fattore, Mason and Watson, 2009, p. 64) have the potential not only to impact negatively on their health but also to adversely affect both their sense of self and of self-integrity.

*Information Management* – the attempt to control information relating to their conditions by the chronically ill. This coping strategy is used to prevent negative experiences and/or outcomes in contexts believed to involve difficult people and/or situations. Much of the evidence relates to the circumstances surrounding decisions, particularly on the part of those with invisible illnesses,

to disclose or to conceal their illnesses (Joachim and Acorn, 2000). In the case of CF, 'there is no convention of disclosure or concealment for [people] to draw on as a guide' (Jessup and Parkinson, 2010, p. 358). Nevertheless, it has been reported that adults with CF make decisions based on the level of risk they attach to disclosure in individual circumstances, i.e., whether low, medium or high (Lowton, 2004). For adolescents with CF, the problem appears to be a general concern that disclosure could draw attention to the ways in which they might differ from their peers, thus perhaps jeopardizing peer acceptance, a central focus of this age group (Berge *et al.,* 2007). However, a perceived lack of knowledge and, therefore, of understanding of CF in lay environments is a contributing factor, though an assessment which is not confined to people with this condition (cf. Williams, Gannon and Soon, 2011, for example). Moreover, not feeling especially knowledgeable themselves regarding their illnesses and, in the case of adults with CF, not even being able to 'see themselves' in the literature (Widerman, 2003, p. 97), further complicate matters. It is hardly surprising, therefore, that the 'chronically ill and disabled people often become masters at reading cues' not only about when to disclose but also 'about how much to tell' (Charmaz, 2002, p. 317). And yet, not disclosing such an important aspect of their lives, in particular on the part of adolescents, can place other aspects at great risk (Warner and Hauser, 2009), including the nature and quality of their interactions, the management of their care and potentially also their medical outcomes.

### 2.4.4   *Hoping*

The literature in this area concerns the effect that having a chronic illness, including CF, has both on people's hopes for the future and on the identities they might hold in the future, i.e. their future identities. The underlying assumption in such research is that one's hopes for the future and one's future identities are important. This is held to be the case due to the potential impact of people's hopes and future identities on their current actions and well-being. Much of this research is descriptive, however, as distinct from predictive; moreover, it tends to deal with the role of future identities in the context of life tasks and to neglect to examine their role in relation to life problems/setbacks (Oyserman and James, 2011). It also appears to promote a degree of tension between child well-being, or quality of life in the present and well-becoming, which has a future-oriented dimension, rather than acknowledging the complementarity between these concepts, especially where children are involved (Frønes, 2007; Uprichard, 2008). Such an approach is particularly important in the case of chronically ill children, including those having

CF, for whom the future is still tentative and 'the here and now ... a resource that is far too precious to waste' (Sartain, Clarke and Heyman, 2000, p. 918).

Nevertheless, that people develop sets of beliefs not only regarding who they are but also regarding who they would like to become (Eccles, 2009) underlies theorizing about the self and is evident from the array of future self terms to be found in the relevant literature: ideal and ought selves (Higgins, Klein and Strauman, 1985; Higgins, 1987), desired and undesired selves (Ogilvie, 1987), possible selves (Markus and Nurius, 1986; Oyserman and Markus, 1990a, 1990b), fantasy selves (Bybee *et al.,* 1997; Oettingen, Pak and Schnetter, 2001). The realization of such future selves or identities appears to be predicated, for the most part, on at least the following conditions: whether they feel connected to the current self, whether the actions needed to attain them feel congruent with the current self and whether any difficulties encountered are interpreted as meaning that they are important rather than impossible to attain (Oyserman and James, 2011). In addition, temporal distance matters, i.e., whether the future feels proximal, local and concrete or distal, global and abstract (Trope and Liberman, 2003; Pronin and Ross, 2006; Wakslak *et al.,* 2008). Given such conditions, it is not difficult to understand why the chronically ill, in light of the constraints applying to them in terms of their overall sense of self, expectations and individual prognoses, should adopt rather short-term, albeit adaptive, approaches to the issue of their future identities. Making 'identity trade-offs, in other words, opting for one identity over another, as they weigh their situations and losses and gains', they change their future identity preferences in line with their needs and conditions, some appearing to 'assume that they will realize their preferred identities', others keeping 'a watchful eye on their future selves and emerging identities' (Charmaz, 1995, p. 659). In terms of those having CF, there 'are minimal … studies regarding adaptation not only to the adult body the incumbents once thought they might never have but also to the future for which they often have only tentatively planned' (Jessup and Parkinson, 2010, p. 359). However, adults with CF have been found to report 'lower levels of hope', relative to healthy controls, on the Hearth Hope Index, especially in relation to the term "scared about the future" (Abbott, 2009, p, 34). The picture with regard to adolescents having CF, while equally slight, nevertheless suggests a relatively optimistic situation: they appear to be defining goals for the future (Lannon Palmer and Boisen, 2002; Jessup and Parkinson, 2010) and, in the majority of cases, to be hopeful and positive in respect of it (Szyndler *et al.,* 2005; Abbott, 2009).

Research relating to the content of the future identities people hold appears to suggest the equivalent of a developmental trajectory in line with specific life phases.  In this regard, that adolescents with CF have been found to be strategizing goals which include graduation, career, travel and marriage (Lannon Palmer and Boisen, 2002; Jessup and Parkinson, 2010) is encouraging.  However, that the identity moratorium phase (a phase of identity development characterized by exploration of one's potential life choices in the relative absence of commitment in these regards, cf. Marcia, 1966) has been associated both with a greater number of future identities generally and with more negative or feared future identities than any other such phase (Dunkel, 2002) is interesting; the position regarding the effect that having a chronic illness, including CF, may have on the balance of positive and negative future identities among children in this identity phase is not known as it has not been studied.

That the future identities people hold and appear to be very reluctant to relinquish (Carroll, Shepperd and Arkin, 2009) affect current behaviour and well-being has been alluded to above. In this regard, the research in relation to behaviour has indicated effects, over time, across the domains of academics and health – though the latter did not involve the chronically ill (Ouellette *et al.,* 2005; Hoppmann *et al.,* 2007); studies focusing on the effects on well-being have indicated that to merely contemplate a positive future identity may result in elevated mood and a sense of optimism regarding the future; however, the effect of negative or feared future identities may be greater (Oyserman and James, 2011).  Again, while some of this research has involved the mentally and physically ill (Janis, Veague and Driver-Linn, 2006; Kindermans *et al.,* 2010), little is known regarding the consequences of their future identities, either positive or negative, for chronically ill children, including those having CF. However, that their 'futures' have relevance for their 'presents' seems clear and, given the extension which they now have on these futures, that they should be acknowledged for their intrinsic value and, indeed, anticipated with a certain optimism seems appropriate.

### 2.4.5   *Schooling*

The literature in this area concerns the effect that having a chronic illness, including CF, has on the experiences of children making their way through school.

This effect is conceptualized, primarily, in terms of academic outcomes, the general consensus being that 'educational achievement' has 'acquired almost cardinal status as an aim for youth' (Soutter, Gilmore and O'Steen, 2011, p. 612). That such an aim may represent a considerable challenge in the case of the chronically ill is, nevertheless, a reality given that although most childhood conditions do not give rise to organic brain damage, it would appear that very nearly 40% of children and adolescents with chronic illness experience academic problems (Taras and Potts-Datema, 2005; Wray and Radley-Smith, 2010). It has been reported, for example, in relation to certain diseases of the heart and/or lungs, including CF, for which 'there is no documented evidence … [of] … any cognitive or neurological impairment' that measures of cognitive function and of academic ability revealed results which 'were significantly lower than those of the healthy group' (Wray and Radley-Smith, 2010, p. 2527). While attempts to explain such findings in the literature are hampered due to lack of comparability of health conditions and of understanding of specific contributory factors and associations, possible elucidations having relevance in the current context reference issues such as attention deficits, fatigue, nausea and the side effects of surgical procedures, of anesthetics and of medication. In addition, there is the matter of student absenteeism, a regular feature of life for children having CF. This appears particularly important given that 'academic problems are … likely to be noted in those subjects that build upon earlier learning and require continuous school attendance' (Duggan, Medway and Bunke, 2004, p. 155). Also highlighted in research relating to CF and having an educational focus, are the effects of age of diagnosis and of nutritional status on cognitive development. In this regard, it has been found that a delayed diagnosis, resulting in prolonged malnutrition, leads to impaired cognitive development (Koscik *et al.,* 2004); however, it must be stated also that nutritional factors remain problematic for children with CF and become increasingly challenging during adolescence (Lai, 2006; White *et al.,* 2007).

Given that their educational achievements are likely to be somewhat compromised, at a minimum, it is not surprising that anxiety about poor school functioning has been reported in relation to children with chronic illness and CF. This is held to arise because such children understand 'the importance of school' and 'the long term impact of not doing well' (Foley *et al.,* 2012, p. 383), in those activities which are typically valued in that environment. Indeed, that academic success may constitute a core part of their identity at this time, and, as a consequence, that their self-esteem may be largely contingent upon this form of success is perhaps to be expected (Heppner and Kernis, 2011). In such circumstances, where children essentially fail to

experience the positive recognition which accompanies success at school and to enjoy the concomitant rewards, including feelings of competence, they are unlikely to feel good about themselves (Fattore, Mason and Watson, 2009). Moreover, they probably have concerns regarding their performance relative to their school peers (McCaslin, 2009), not being able to keep in step with them across a range of domains proving problematic for children with CF (Jessup and Parkinson, 2010).

This raises an additional issue: their lack of freedom, due to their illnesses and to the demands of their medical regimens, to engage in non-academic or extra-curricular activities and therefore to keep in step with their classmates even in relation to pursuits which are typically not valued in the classroom. The frustration they experience in this regard arises because they understand that these pursuits have the potential to provide them with positive recognition outside the classroom, an outcome which frequently has the effect of enhancing a student's overall level of respect within the peer group. Moreover, not being in control of decisions relating to their 'free' time, they lack the autonomy to practise activities likely to grow their strengths and capabilities generally. Being denied this form of benefit and satisfaction also, including the associated feelings of self-efficacy so necessary for well-being (Fattore, Mason and Watson, 2009), it is difficult for them to develop the skills they will require 'to occupy a valued role in society' (Foley *et al.,* 2012, p. 385) and to realize their full potential.

Indeed, for some chronically ill children and adolescents, the world of school poses challenges on a daily basis. Those having CF, for example, experience a degree of scrutiny at lunch-times, in relation to their compulsory enzyme-taking exercise, which appears to get 'featured without exception in participants' dialogue' (Jessup and Parkinson, 2010, p. 357). Their uncommon routines, often relatively small stature and invariably unreliable bodies and functions combine to 'out' them in an environment where the issue of whether or not they are welcome, a concern for all children (McCaslin, 2009), takes on additional significance due to their particular situations. That there appears to be little knowledge and understanding of the plight of the chronically ill generally, in this environment (Duggan, Medway and Bunke, 2004; Hutchinson and Hall, 2007), complicates matters. In this context, it has been reported that teachers are, in the main, ill-informed with regard to their students' medical conditions and ill-equipped, therefore, to implement appropriate supports and/or inclusion practices in respect of them (Meuleners *et al.,* 2002; Duggan, Medway and Bunke, 2004). Moreover, they are likely to be largely unaware of

the rather unwelcome experiences of some such students, e.g., being teased, labeled, bullied; having explanations queried, difficulties minimized, conditions trivialized. In fact, such experiences seem to occur throughout their schooling for some ill adolescents, becoming particularly problematic at transitional periods involving changes of class/year and/or school (Williams, Gannon and Soon, 2011). Given that it matters whether the significant adults in schools care not just about their students' learning but also about them as individuals (Waters, Cross and Runions, 2009; Soutter, Gilmore and O'Steen, 2011), practices having the potential, albeit unwittingly, to imply any ambivalence in these regards and to function as barriers for the chronically ill experiencing the kind of closeness to others which signals acceptance (Vignoles, 2011), merely intensify their vulnerabilities in an already demanding arena. Witness, for example, the finding in relation to pediatric liver transplantees 'that how they appeared to others was often more important than how they appeared to themselves' (Wise, 2002, p. 80); the fact that many students are reluctant to disclose details of their conditions in school, connections and friendships being regarded as 'an integral part of school life' (Foley *et al.,* 2012, p. 381) and, at times, as more important than compliance with medical regimens.

Irrespective of students' tendencies with regard to adherence to treatment schedules, however, the fact of having a chronic illness and, in the case of CF, a 'wayward body … [which] … rather than errant … is conversely compliant, conforming to the genetic script with which it is programmed' (Jessup and Parkinson, 2010, p. 359), results in a level of disruption for many school-going children which can be difficult to avoid but which can affect their immersion in school life. While it is acknowledged that repeated and sometimes prolonged absences, due to illness, may lead to academic difficulties for some chronically ill children, other difficulties may also arise. Research has shown, for example, that on return to school and finding that, although in the company of their friends, they still cannot take part in activities with them, either due to physical problems or because so far behind that their input would be unhelpful, certain chronically ill children experience a loss of direction, a loss of meaning and a loss of ability to find alternative solutions to their dilemmas (Griffiths, Schweitzer and Yates, 2011). Given that it is not only the act of participating which matters, but also the quality of the involvements in terms of structure, variety and perceived value (Hansen, Larson and Dworkin, 2003; Markstrom *et al.,* 2005; Busseri *et al.,* 2006; Dolan, Peasgood and White, 2008; Fredricks and Eccles, 2010; Soutter, Gilmore and O'Steen, 2011), it is conceivable that where such opportunities are restricted, one's capacity to experience a broad education may be adversely affected. In this context, it is significant that the

educational mission statements of schools worldwide highlight the importance of student engagement (Soutter, Gilmore and O'Steen, 2011). It is noteworthy, too, that school engagement and activity participation have been included both by Theokas *et al.,* (2005) in their Index of Thriving and by Guhn *et al.,* (2012) in their Overall Health and Well-being Composite. However, it is also the case that when unable to fully partake in school life, students may experience a degree of tension 'between a sense of isolation and valued participation' (McCaslin, 2009, p. 143) and ultimately fail to realize their personal potential.

## 2.5   Perspectives on Disability

The sociological literature on people with chronic illnesses such as those referred to above, including CF, depicts them as disabled and 'presents disability as either biological or social in origin or as foremost a medical or a social issue' (Rhodes *et al*., 2008, p. 392).

On the one hand, there is a body of work which focuses on the corporeal existence of impairment and which essentially involves framing the individual as disabled by virtue of his/her impairment. Such theorizing reflects a medical-model approach to disability which equates impairment with biological inferiority and imperfection. Not conforming to the norm, impaired bodies require corrective or curative treatment, the objective being 'to afford the greatest approximation to mainstream notions of normality' (Roulstone, 2011, p. 379, referring to Oliver, 2009).

But what does 'normal' mean? In the current context, it would appear to refer to that space being occupied by the non-impaired or able-bodied. Does this mean that the impaired and incurable are forever relegated to a different space? The concept of distance between the impaired and the non-impaired is frequently addressed in the literature in terms of difference, the dominant discourse in this regard pointing to what is generally referred to as the rhetoric of tragedy. In this storyline, to be impaired, abnormal, different, evokes values bordering on worthlessness. Moreover, this is a story of personal tragedy, in which reductionist understandings not only prevail but also justify the medical model approach to disability which, in essence, identifies the phenomenon as an issue of impairment.

On the other hand, there is a substantial body of work which focuses on the sociological dimensions of disability, the commonality of socially constructed barriers faced by people with

impairments and effectively disabling them.  In this more recently delineated standpoint, the phenomenon is identified as an issue of disablement by society, or 'disablism'.  Termed the social model approach to disability, it is accredited to the Disabled People's Movement and to the Union of the Physically Impaired Against Segregation (UPIAS) in the UK, which defined disability as 'something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society' (UPIAS, 1976, p. 4). In this model, the emphasis is on the discrimination and oppression experienced by disabled people and on the need to tackle same from a global human rights perspective.

While such an approach facilitated a shift in focus from a medical discourse of an individual's misfortune to a discourse of societal change, it also explicitly rejected the notion of a causal link between impairment, a physical, sensory or intellectual limitation and disablism, the social, material and cultural barriers faced by the disabled.  Indeed, the issue of impairment is considered largely irrelevant in the context of disability discrimination; medicine too is regarded as ineffective in the fight against the disabling practices of society.  Hence, the argument that a clear distinction between the two 'is necessary if disability is to be fully understood as a basis for identity politics' (Hughes, 2009, p. 679).

However, efforts to keep 'impairment off the agenda of disability debate' (Hughes, 2009, p. 684) did not succeed, calls to bring 'bodies back in' (Loja *et al.,* 2013, p. 191, citing Zola, 1991) being positively received.  The relevant literature suggests a growing recognition of the need to consider alternative discourses, to engage in fresh thinking since neither the medical nor the social model appeared, separately, to adequately capture the lived experiences of disabled people.  In this context, the acknowledgement by Shakespeare and Watson that 'people are disabled both by social barriers and their bodies' (Hamilton, 2009, p. 642, citing Shakespeare and Watson, 2001) was particularly significant given that it represented a rejection of a basic tenet of the 'strong' social model with which they had been associated for so long.

The development by Thomas of her social-relational model in 1999 (Thomas, 1999) marked a significant step forward in the effort to recognize a relationship between impairment and disablism.  Providing an extended social model, she argued for a social-relational definition of disability.  This definition acknowledges that apart from social forms of oppression, people also experience restrictions in activity and psycho-emotional effects as a consequence of their

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impairments (Mortier *et al.,* 2011), i.e., they experience both structural and psycho-emotional effects resulting in what she termed 'barriers to doing' and 'barriers to being'. Such acknowledgement of the personal experiences of disabled people as incorporating the effects both of impairment and of disability discrimination facilitated recognition of a range of disabling experiences and appreciation of the richness of the lives of disabled people.

The re-emergence of the body and of a certain 'corporeal realism' (Hughes, 2009, p. 684, referring to Shilling, 2005) in disability discourse has been accompanied by a corresponding revival of interest in 'recovering this lost corporeal space' (Loja *et al.,* 2013, p. 191). The latter is reflected in the growth of a range of new biosocial movements in health involving networks of mutually supportive individuals that are 'often defined by a common chronic condition which technocratic medicine has limited powers to ameliorate' (Kendall and Rogers, 2007, p. 133). Focusing on such medical conditions and on issues of biological existence, biomedical diagnosis and classification, genetic status and cure these movements also promote user-friendly clinical care, de-stigmatization, civil rights and social inclusion, i.e., they prioritize impairment over disablism. In this regard, it has been stated that the 'biological citizens' who populate these movements are more likely to attribute disability discrimination to 'the tyranny of biological norms, rather than as a consequence of a disablist social structure' (Hughes, 2009, p. 680).

## 2.6   Critique of Disability Models

A singular problem with the medical model, as a pathologising gaze, relates to its reductionist understandings and privileging of professional discourse in relation to what may constitute 'the best interests' of people with impairments. The literature in this area demonstrates the value of considering alternative discourses and the need to develop 'multi-situated understandings of the lives disabled people lead' (Simmons, Blackmore and Bayliss, 2008, p. 734). Constructions of normality which conform to the able-bodied, ideal type are increasingly challenged, the vulnerability of the 'clean and proper body' being exposed (cf. Hughes, 2009, p. 403). Impairment itself has been deemed an 'unstable category' (Hamilton, 2009, p. 643), the variability and proliferation of impairment categories in the post-modern age generating discussions regarding its validity in the context of what has been termed 'the hunt for disability' (Hamilton, 2009, p. 642). The concept of cure in this model presumes a desire to be cured and an abhorrence of 'undesired differentness' (Beauchamp-Pryor, 2011, p. 6). Such assumptions have

implications associated with identity which go to the heart of what it means to be disabled and which call the medical perspective on disability seriously into question.

Arguably the most frequently articulated criticism of the social model relates to its exclusion of the body, the site of physical impairment, from disability discourse (Loja *et al.,* 2013). While the relevant literature suggests that this strategy was implemented for political reasons (Hamilton, 2009), it is becoming increasingly clear that there is a need to recognize and to focus on the relationship between the impaired body and disability discrimination (Beauchamp-Pryor, 2011); indeed to reject 'modernist binaries' (Hamilton, 2009, p. 642) which fail to address all dimensions of the disabled experience has become ever more acceptable.  With regard to the latter, the homogenization of disabled people, even for strategic purposes, has been questioned (Islam, 2008), neglect of the individual experience becoming less common in studies of both the disabled and the able-bodied.  A related issue concerns the dangers inherent in a lack of emphasis on notions of personhood for one's fundamental sense of self (Simmons, Blackmore and Bayliss, 2008).  As Islam (2008) puts it: 'group membership is not simply synonymous with identity formation, no-one is reducible to one singular identity' (Islam, 2008, p. 49).

## 2.7   Identity and Disability

The discourse of identity intersects with that of disability, connecting up with the diverse perspectives propounded in the dominant models, as outlined above, in largely complementary ways.

On the one hand, 'disability has been stigmatized as a negative identity' (Loja *et al.,* 2013, p. 198) in accounts which are underpinned by a medical model approach. This is due, in the main, to the othering concept inherent in the model which  'has shaped the understanding of disability as ... deficit' (Loja et al., 2013, p. 198) and as 'flawed' existence (Hughes, 2007, p. 673).  A disabled identity is construed, primarily, as incorporating 'functional limitations' (Cunnah, 2015, p. 217) which dictate exclusion from decision-making and imply capacity to make but inadequate contributions to society.  Moreover, the disabled, in this approach, are identified as essentially passive objects who require professional help and whose disempowerment can be justified accordingly (Vlachou and Papananou, 2015).

The difficulty with such theorizing is that it fails to take account of the experiences of disabled people themselves and of the link between such experiences and the construction of identities. In this regard, it would appear that it is their daily life experiences which matter; an over-emphasis, therefore, on 'physical or biological dimensions related to disability .... may narrow the understanding of ability and what is felt as normal for persons' (Bekken, 2014, p. 789). A further difficulty relates to the failure to acknowledge the fact that, irrespective of their diagnoses and of their attitudes to same, the disabled have been reported to exercise agency in relation to their identities and to refuse to accept their ascribed identities, choosing instead to either incorporate, downplay, conceal or transform 'different aspects of their identities at different times and in different contexts' (Rhodes, 2008, p. 387). Such an approach seems to also apply in the case of those having congenital impairments, reinforcing Shakespeare's assertion that 'disabled people are not their impairments' (Beauchamp-Pryor, 2011, p. 11, citing Shakespeare, 2004). In addition, to fail to recognize the impact of those disabled activists who engage with the medical and scientific community for the purpose of progressing issues relating to their particular conditions is to misrepresent the disabled identity as currently understood.

On the other hand, social model thinking has had a significant positive impact on disabled identity. Shifting the focus from impairment to societal repression and discrimination, it 'assumes a single, unifying and essential identity' (Rhodes, 2008, p. 388), a strategy which has had a liberating and transformative effect on the disabled enabling them to feel angry about their situations rather than ashamed of their shortcomings (Shakespeare, 2006; Cunnah, 2015). Viewing identity and self 'through an analysis of oppressive social relations' and focusing 'on changing society and empowering disabled people' (Islam, 2008, p. 41), this model has contributed to an optimistic vision of disability and a celebration of disabled identity.

Looking more closely at this approach, however, it is clear that any potential benefits to disabled people are predicated upon acceptance of a narrow but firm definition of disability as social oppression. The difficulty with such a position is that it may be equated with 'locating the burden of responsibility for change at the social level (i.e. on other people) ... [a strategy which] ... downplays the potency of individual agency and lurches towards a victim mentality, not of personal inadequacy ... but of societal failings' (Rhodes, 2008, p. 393). A particular obstacle relates to the additional requirement of self-identification as a disabled person. The literature is replete with examples of the reluctance of people to so identify in circumstances which facilitate

this and which, accordingly, help to minimize a sense of difference, i.e., when the impairment is not especially visible, when the condition is perceived to be relatively less disabling vis-à-vis other conditions, when the individual is no longer impaired, or cured, but an outsider in an ableist world (Beauchamp-Pryor, 2011). For many, to share a common identity as disabled with others experiencing disablism would not appear to be a priority. Indeed, the evidence would suggest that shared experiences do not necessarily imply shared perspectives, the reality being that people construct multiple identifications which they use flexibly as they deem appropriate (Hussain 2003, Islam, 2008).

Biological citizens regard biology as an important basis for identity. Claiming a particular diagnostic category as part of their identity they embrace a medicalised self which is constructed in biological terms and which responds most efficaciously to biologically-based solutions. While assuming a collective illness identity, they nevertheless take a proactive role in the curative process, participating in the quest for genetic treatments, amassing specialized knowledge relating to their medical labels and partnering the professionals in a spirit of concordance. Thus, they are enabled to identify as autonomous and responsible citizens and to face the future with a degree of hope.

In this post-medical age, it is difficult not to conclude but that 'a disembodied view of disability is no longer tenable' (Hughes, 2009, p. 686) despite the arguments being advanced in this regard by some social modelists. Not only is the body 'the site of physical disability' (Loja *et al.,* 2013, p. 191) but efforts to 'explain away the biological existence of impairment' (Rhodes, 2008, p. 388) cannot succeed. Moreover, as the literature on the rise of various condition-based groups illustrates, many disabled people view their impairment as the primary cause of their disability, regarding the latter as essentially medical in origin. That this is likely to apply to the chronically ill, in particular, has been argued by Williams (cf. Hughes, 2009, p. 684, referring to Williams, 1999) who is very clear that to claim otherwise, in their case, is simply erroneous.

However, this is not to deny the existence of disablism and the significance of the contribution of the social model approach to the lives of disabled people. To reconceptualize disability 'as a product of structural and environmental inequities and not simply an attribute of individual impairment' (Simmons, Blackmore and Bayliss, 2008, p. 733) has not only been visionary and emancipatory but has also facilitated an appreciation by the disabled in particular 'that societal

changes are necessary in order to stem the tide of ableism' (Hamilton, 2009, p. 641). Given such an agenda it seems clear from the literature that, as a political tool, the model has been ideal, i.e., 'it was easy to explain, its implications were obvious' (Sheldon *et al.,* 2007, p. 215, referring to Shakespeare, 2006). In this context, it would appear to have delivered much reform in legislation and policy which has meant that many disabled people have been enabled to access higher education and to acquire independence through employment, laudable achievements which will assist the effort 'to abrogate the negative ontology that has haunted disability throughout modernity' (Hughes, 2009, p. 686).

Thus, in sum, the discourses of identity and of disability reveal a growing consensus regarding the relevance both of the impaired body and of disablism in the current context. Moreover, it is becoming increasingly clear that the experiences of disabled people matter and contribute to the identity construction process. In addition, that they exercise agency in relation to their situations and display a multitude of identities across same, suggests that the nature of the journeys disabled people undertake in an ableist world may indeed be rather complex.

# Chapter 3. Methodology

## 3.1 Introduction

This chapter begins with an outline of some key aspects of my chosen methodology. It then presents details of the process undergone in the effort to recruit suitable participants. The data collection stage is described in terms of the following five components: the in-depth interview, construction of the interview schedule, construction of the research questions, execution of the interviews and the tape-recording and transcription exercises. My approach to the analysis of the data collected is also delineated as involving a series of steps: looking for themes in the first case, connecting these themes and looking for themes in the other cases. Finally, the chapter concludes with a discussion of research ethics. The Timeline for the research and for the production of this research report is presented in Appendix A, p. 145.

## 3.2 Methodology

Given my world view as outlined above and my particular research paradigm, Interpretative Phenomenological Analysis (IPA) appeared to me to represent the most appropriate methodology in the current circumstance. While a relatively new but rapidly growing and distinctive approach to qualitative and experiential research in psychology, it also, and significantly from my perspective, has strong theoretical links not only with phenomenology and hermeneutics, as the title indicates, but also with idiography.

In IPA, the 'aim … is to explore in detail how participants are making sense of their personal and social world and the … currency … is the meanings particular experiences, events, states hold for participants' (Smith and Osborn, 2008, p. 53). The approach is phenomenological in that its focus is on the participant's lived experience and on his/her personal account of that experience. However, it recognises the centrality of the researcher in this process in terms of access to and analysis of that personal 'life-world'; it recognises that such an exercise 'inevitably becomes an interpretative endeavour for both participant and researcher' (Smith, Flowers and Larkin, 2009, p. 37). In effect, 'a two-stage interpretation process, or a double hermeneutic, is involved. The participants are trying to make sense of their world; the researcher is trying to make sense of the

participants trying to make sense of their world' (Smith and Osborn, 2008, p. 53). The final analytic account, therefore, includes the joint reflections of both the participants and the researcher.

## 3.3 Participants

The participants in this study were selected because they had been formally diagnosed as having CF and because they reported a history of schooling. I was particularly keen to talk to children at critical transitional points in their schooling. In terms of the Irish education system, this essentially meant that the children had to be in $5^{th}$ or $6^{th}$ class (10 to 12 years of age) and transitioning to second level education, or in the Leaving Certificate cycle and transitioning to third level education. Given the relatively small cohort of children likely to fulfil these key criteria I decided that the most efficient way to deal with the issue of recruitment was to seek the assistance of the CFAI. This is a voluntary organisation which was set up by parents, in 1963, for the purpose of improving the treatment, facilities and well-being of people with CF. It has a high public profile, an excellent track record in relation to its various campaigns and branches across Ireland which actively promote the needs of individuals and families affected by CF. The CFAI, together with the CFRI, which aims to enrol all patients with CF on its database, has access to up-to-date information on virtually all aspects of CF in the country. I was soon to discover, however, that this did not include information relevant to my study.

Having contacted both the CFAI and the CFRI, it was immediately clear that research having a non-medical focus would be novel and timely. Indeed, such has been the concentration of effort, albeit most successfully, on medical issues that neither organisation had the kind of data which I required. Even the most basic information was lacking, e.g. numbers of children attending first or second level schools, numbers transitioning to college. It must be stated, however, that the respective remits of these organisations had never included the collection of such data; moreover, given the extraordinary health/treatment issues faced by people with CF and, until relatively recently, the unpromising nature of survival rates, that other data should have been prioritised is understandable.

Nevertheless, due to the enthusiasm and creativity of the staff with whom I interacted, it became possible to access the information which I needed for my study. In this regard, my first course of

action was to post a Recruitment Advertisement (Appendix B, p. 146 ) in the CFAI's bi-monthly newsletter, entitled Spectrum.  This appeared in Issue 28: July/August 2012.  Unfortunately, it met with a 'nil' response.  The reaction of the CFAI to this development was encouraging, however.  It was pointed out that Issue 28 coincided not only with the long-awaited announcement regarding the opening of a new CF Unit in St. Vincent's Hospital, Dublin but also with the summer holiday season!  Accordingly, it was decided to repeat the Recruitment Advertisement in Issue 29: September/October 2012.  This met with some success in that it led to a number of conversations with interested and supportive parents;  however, only one of these exchanges yielded a positive result.  The reasons were clear-cut: either the children did not meet my criteria in respect of age and level of schooling or they were unwilling to get involved.  With regard to the latter, it is not possible to provide much detail having guaranteed confidentiality to all respondents in relation to our discussions.  Nevertheless, I can reveal that in some of these instances, the children were reportedly becoming increasingly reluctant to discuss their CF and inclined to exhibit behaviours which suggested that they were having difficulty coming to terms with their situations; in other instances, they did not wish to participate in anything having a connection to their school lives.

Building on the above experience and encouraged by the nature of many of my exchanges with these parents, I decided to contact all CFAI branches in Ireland and, with the support of the organisation which supplied me with the relevant information, to ask directly for help with the recruitment of suitable participants.  The response was as instructive as it was generous.  Mothers and fathers of children with CF talked openly about their hopes, fears and dilemmas; they also checked their respective areas for suitable participants and put me in touch with other families where appropriate.  Having made and received many phone calls, it became obvious that the number of  children meeting my criteria and both willing and well enough to take part was miniscule: excluding the participant already recruited, the total was 4.  Of these, all but one agreed to participate; the latter was male and after some consideration decided not to get involved.  This meant that my sample would only include one, as distinct from two, males as originally envisaged.  At that point in time, I renewed my efforts to recruit a second male, but to no avail.  When it became clear that I would not succeed in recruiting another male, I invited the remaining female, who had been willing to get involved, to participate.  Thus, my sample consisted of one male and three females (Table 3.1)  It transpired that one of these girls was

subsequently taken ill and unable to see me until some weeks after I had concluded my meetings with the other participants.

| Children's Pseudonyms | Children's Ages |
|---|---|
| Participant 1: Therese | 16 years |
| Participant 2: Pauline | 16 years |
| Participant 3: Celine | 13 years |
| Participant 4: Louis | 11 years |

**Table 3.1.**    Children's Pseudonyms and Ages

### 3.4  Data Collection

The aim in IPA research and in the current study is to collect rich, detailed accounts from participants regarding their experiences.  In this regard, the data generation methods considered most appropriate include the in-depth interview and the diary (Smith, Flowers and Larkin, 2009). I chose the in-depth interview as I wanted to have an opportunity to engage in a dialogue with each of my participants and to probe areas appearing to have the potential to provide interesting information.

### 3.5  In-depth Interviews

The in - depth or semi-structured interview not only facilitates access to the psychological world of the participant but also enables the co-construction, by both parties, of the event.  Not being the experiential expert in this area, I valued the in-built flexibility which characterises this research tool and which essentially allows the conversation to be guided by the questions on the interview schedule rather than dictated by them.  The permission accorded the participant to influence the direction which the interview might take, indeed to introduce new topics for consideration, signalled a genuine opportunity for me to access 'the thing itself'.  I believe that such situations have the potential to produce rich data and a genuine rapport between participants and researcher.

### 3.6  Constructing the Interview Schedule

In IPA, the primary purpose of the interview schedule is to facilitate appropriate coverage of the range of topics relevant to the research question/s; it also facilitates a smooth exchange between participant and researcher.

In constructing the interview schedule for this study, I found myself being forced to map out the broad agenda which my research would address, to anticipate potential difficulties and to generate clear solutions. In this regard, and drawing on my literature review, I discovered that in examining my participants' journeys through school, I needed to also get a sense of what CF meant to them and of its impact on their lives in general. Thus, I realised that in order to produce a rich contextualised account I would have to examine these areas in addition to my principal concern: the impact of CF on the chidren's identity construction. As I continued to contemplate the latter, therfore, it became increasingly apparent that a thorough understanding of the lifeworlds of school-going children having CF would involve investigation of a range of areas. Accordingly, I settled on the following five content areas or domains of enquiry:

- the impact of CF on the children's school life;
- the impact of CF on the children's sense of self;
- the impact of CF on the children's sense of the future;
- what CF means to the children;
- the impact of CF on the children's sense of life in general.


Having determined the domains of enquiry, I proceeded to arrange same in the most logical and appropriate sequence. In IPA research, the latter tends to denote a strategy which involves having relatively manageable, scene-setting items at the beginning of an interview and working gradually towards more sensitive or potentially difficult items. While it could be stated that the entire issue is sensitive, I was mindful of the remarks made by Smith and Osborne (2008) in a similar situation: '… the respondents know the project is about their health condition and have agreed to talk about it' (p. 61). In other words, the best way to start an in-depth interview may be to allow the participants to talk about themselves; discussion of the impact of CF on their lifeworlds could come later on. Bearing this in mind, together with the conversations I had had with their parents, I decided to open each interview by giving the children an opportunity to talk about themselves, a topic which I believed they would be capable of discussing at some length and without undue difficulty. I planned, at that point, to move on to the issue of CF and of its impact on their lives. This would be followed by discussion of potentially more sensitive areas: its impact on their school and future lives. Finally, I would close each interview by inviting them

to talk about their sense of life in general as people having CF.  Thus, the domains of enquiry would, in the main, be dealt with in the following sequence:

- the impact of CF on the children's sense of self ;
- what CF means to the children;
- the impact of CF on the children's school life;
- the impact of CF on the children's sense of the future;
- the impact of CF on the children's sense of life in general.

## 3.7   Constructing Questions

In attempting this task, I drew on the five domains of enquiry as outlined and sequenced above and, devising a single question to capture the essence of each in turn, I created the following list to guide my work:

- Who are you and why do you say you are who you say you are?
- What is CF and how does it affect you?
- How does CF affect your school life and others' perceptions of you?
- What does the future mean to you?
- How is life for you?

Then, aligning each domain of enquiry (e.g., the impact of CF on the children's sense of self ) and guide question (e.g., Who are you and why do you say you are who you say you are?), I proceeded to construct a set of IPA – appropriate questions, generating one set per domain of enquiry (e.g., five sets of IPA – style questions).  With regard to the latter, I was particularly mindful of the need to construct open questions which would not only enable me to address the topics I wished to research but which would also encourage the children to speak freely and at length about their thoughts and feelings.  I also took care to ensure that the wording in each case was neutral and devoid of jargon.  Moreover, due to a concern regarding the possibility that some questions might still not be sufficiently clear to elicit satisfactory responses, given the nature of the research and the age level of my participants, I constructed a series of prompts to accompany each question.  While this is not a requirement in IPA studies (Smith, 2008; Smith, Flowers and Larkin, 2009), I was anxious to ensure that my participants would engage with the issues and allow me to access their personal lifeworlds.

The final schedule, as presented in Appendix C, pp. 147 - 148 represents the culmination of a number of drafting and re-drafting exercises, discussions with colleagues and suggestions from my supervisor. While it may appear relatively lengthy, I felt that having a range of topics and questions would help to ensure that every participant could contribute and that where a dearth of information applied in an area, that this would generally be offset by a more expansive contribution in another area.

## 3.8 Interviewing

In IPA, the participant takes centre stage in the interview process. As the experiential expert whose lifeworld is the sole focus of attention, much effort is expended on facilitating access to this lifeworld in an appropriate and comprehensive manner. In this regard, I believe that there is a considerable onus on the researcher to create the conditions necessary for delivery of a successful outcome.

Bearing the above in mind, I approached the interview process in terms of a series of stages: the pre-interview stage, the interviewing stage and the post-interview stage. During the initial preparatory stage, I spoke with the parents of those children who had agreed to participate and outlined the format which the interviews would follow. This included making it clear that I did not have a pre-set agenda, that my interest was in their children's experiences. I also explained that there was no preparation involved, that there were no right or wrong answers and no rules regarding the level of detail required in response to any query. The only stipulations related to my need to speak to the children alone and to tape-record our conversations. With regard to the latter, however, I assured them that their children would not be identifiable in my final report, details of which I would share with them if they so wished. I advised them of the fact that I had set out the conditions under which their children would take part in a Participant Information Sheet (Appendix D, p. 149), which I agreed to post to them and the contents of which I asked them to discuss with their children in advance of my visits.

I then addressed the need to have the interviews take place in a comfortably familiar and safe setting which would also be quiet and unlikely to be subject to interruption (Smith, Flowers and Larkin, 2009). Since many of the parents with whom I had been in contact from the beginning, courtesy of the CFAI and referenced above, talked about the difficulties which children with CF

have regarding their illness and its exposure in the school environment, I was reluctant to talk to the children in their local schools.  In reality, the child with CF is likely to be the only pupil in his/her school with the condition; to request that he/she be withdrawn from class for research purposes and interviewed in a separate room did not strike me as either appropriate or respectful.  In the circumstances, therefore, I requested permission to conduct the interviews in each child's home.  I realised that this was a 'big ask', given the burden which families having a child with CF inevitably face on a daily basis, but I considered it important in the context of my particular study.  In addition, because research with children having CF tends, for the most part, not only to have a medical focus but also to be conducted in hospital settings, I felt that such an arrangement had the potential to mark my study out as relatively unique and to enhance my ability to access 'the thing itself'.  The families could not have been more supportive.  We discussed suitable dates and agreed, in light of the subject matter, to hold the interviews after the holiday period, when the children would have settled back into school and resumed their journeys through that world.  We also agreed suitable times, on the understanding that my visits were likely to take approximately one hour and that at least one parent would have to be present in the home throughout that period.

As I approached the interviewing stage, I found myself memorising the interview schedule, role-playing with my children, envisioning the sequence of activities, checking the requisite forms and reflecting on the journey which I was about to begin.  It seemed to me that a critical success factor was the need to establish a good rapport with the children from the moment I arrived in their homes.  In this regard, having their parents to introduce me and to support me as I went through the Participant Information Sheet and answered their questions was really helpful.  Indeed, I found that by the time I got to the issue of consent, both parties were eager to provide me with written consent (Forms for Participants and for Parents, Appendices E and F, pp. 150 - 151) and I was content that same could truly be described as 'informed'.

Interviewing the children was both a privilege and a challenge for me.  I was conscious of being in the presence of rather special people whose experiences I was eager to access but also cognizant of my responsibility to facilitate, guide and actively listen at all times.  That said, I found that asking the opening question in my interview schedule ('Tell me a little about yourself _____(child's name)') was so conducive to easy, unrestrained replies that I used a version of it at the start of each interview.  I also dealt with the domains of enquiry in the pre-determined order, set out above, as I found that the children seemed to benefit from having an opportunity to

talk about their current selves before moving on to matters having a more uncertain focus. However, I appreciated not having to stick rigidly to the schedule as there were times, within each domain, when I had to abandon it and follow the children's concerns. I also valued having the series of prompts, particularly when engaging with the younger children whose responses were not always sufficiently expansive. In this regard, those responses dealing with their sense of the potential impact of CF on their future selves seemed relatively more problematic and generally required additional probing. On such occasions, I was especially careful to monitor the effect of my questions on the children and to be alert to any negative reactions on their part. While same did not materialise, I detected a certain sensitivity in respect of one child with regard to the following question: 'How would you describe yourself as others see you at school'? In this instance, I feel that maintaining a mix of serenity and empathy in the face of a degree of silence allowed this child to work through the issues and to move confidently on to other areas.

During the post-interview stage, each child was provided with an individual debriefing session and a Debriefing Sheet (Appendix G, p. 152). The latter included my contact details in the event that the children wished to get in touch with me about any aspect of my study. At this juncture, I also made some notes in relation to each interview, recording my reflections on the process and my observations regarding the interactions which had taken place.

## 3.9   Tape Recording and Transcription

In IPA, a verbatim record of all data collection events is mandatory. Where these involve interviews, this is usually accomplished by making audio – recordings of same (Smith, Flowers and Larkin, 2009). Accordingly, as already alluded to above and having received their consent, I made audio – recordings of my interviews with the children taking part in this study. I accomplished this by using the following digital audio - recording device: an Olympus Digital Voice Recorder, WS – 811, DNS version. This multifunctional stereo recorder is small, light and easy to use but effective. However, as I was keen to ensure full audio coverage of my interactions, I also used a second device as a back-up: an Olympus Digital Voice Recorder, DS – 4000. This is equally manageable and effectual. The children had no issues in relation to these devices; if anything they were interested in helping to ensure that they worked properly.

Transcription of audio – recordings in IPA is quite time - consuming in that it involves a record of the entire event, inclusive of the interviewer's questions; indeed, it involves a record of all the words spoken, of all false starts, of all significant pauses and hesitations, of all noteworthy non-verbal utterances (e.g., laughter), etc. This is necessary as the aim is to conduct an analysis at the semantic level. Notwithstanding these requirements, however, having personally worked through each audio – recording, adhering to the procedures as prescribed, I feel not only that such detail is warranted but also that the exercise enables one to develop a familiarity with the accounts which can foster a sense of the task being manageable.

## 3.10   Data Analysis

Analysis in IPA is a multifaceted process.   At one level, it involves attempting to understand the content and complexity of the meanings which participants make of their lived experiences; at another level it involves attempting to engage 'in an interpretative relationship with the transcript' as 'those meanings are not transparently available' (Smith and Osborn, 2008, p. 66). The outcome, therefore, is necessarily 'a joint product of the participant and the analyst' (Smith, Flowers and Larkin, 2009, p. 80).  In practical terms, this final product becomes realizeable through adherence to a set of guidelines which have been specifically but flexibly designed to comply with the principles of IPA.  In the sections which follow, I will describe my personal approach to the application of these guidelines and to the analysis of my participants' accounts.

## 3.11   Looking for Themes in the First Case

In line with the idiographic commitment which underpins IPA, I began by examining one interview in detail, that which I considered to be the most complete, multifaceted and engaging (Smith, Flowers and Larkin, 2009).  This involved reading and re-reading the transcript and immersing myself in the data.  As I did so, I inserted my observations regarding items which I considered noteworthy, as per the guidelines.  However, I became very conscious of the fact that each reading produced new insights and fresh connections between sections of the transcript.  In this circumstance, I also became very conscious of the need to focus on the data and to bracket off my personal views and experiences; recording the latter in my journal and putting that aside for future reference proved satisfactory.

Focusing on the data entailed the compilation of exploratory comments at three different levels (Smith, Flowers and Larkin, 2009):

- the descriptive level – comments which focused on the content of what the child had said, the subject of the talk within the transcript;
- the linguistic level – comments which focused on the specific use of language by the child;
- the conceptual level – comments which focused on the meaning of the content and which included some interpretation of what the child had said.

Recording these different comments in the right hand margin of the transcript, I combined them using the following conventions: normal text for descriptive comments, italic text for linguistic comments and underlined text for conceptual comments. This resulted in an expanded data set: the original transcript and the exploratory comments.

Having concluded this process in relation to whole of the transcript, I then began the search for emergent themes. This involved returning to the beginning of the transcript and, using the expanded data set, simultaneously reducing the volume of information whilst maintaining complexity and identifying theoretical connections within and across the account. Since this exercise entailed breaking up the child's account and working on discrete chunks of material (Smith, Flowers and Larkin, 2009) I decided to approach the task by tackling the transcript in terms of the sequence of domains of enquiry with which it dealt. Thus, I treated each domain of enquiry as a discrete chunk of material, the questions posed in relation to it becoming the focus of my search for themes. While I found that this approach made the analytic effort more manageable, the task of devising concise but precise statements which captured the core features of these chunks of transcript, transforming them into themes, was quite challenging, however.

## 3.12 Connecting the Themes

I approached the search for connections between themes by taking those emerging within each separate domain of enquiry and associated set of questions and systematically seeking a more anaytical ordering in relation to them, based on what appeared to make sense to me. In this context, I made use of a variety of methods: putting like with like, looking for oppositional relationships, noting the frequency of occurrence of particular items, identifying connections

based on specific events or functions.  While I did most of this as a paper exercise, literally moving themes around on a large table, once these themes began to cluster together I found myself making increasing use of my computer to support the mapping process.  During this phase of the process, I took care to check my interpretations against the child's actual responses to the individual questions posed in respect of each domain of enquiry, a practice which brought me back, repeatedly, to the primary source material, sections of which I began to highlight as illustrative of individual themes.

Having completed the above exercise, I summarised my findings by presenting the 5 lists of themes in a series of tables, one for each domain of enquiry, i.e., five tables of themes.  I ordered these themes as coherently as possible and, to facilitate the location in the transcript of instances of each in turn, I added the following identifiers: key words/phrases from the particular extract plus the page number of the transcript.

### 3.13   Looking for Themes in the Other Cases

My approach to the search for themes in the other children's accounts was similar to that described above in relation to the first transcript examined.   This involved bracketing all information in respect of that transcript and working, in rather disciplined fashion, on the next one chosen for analysis.  I must admit that this exercise was not as difficult as one might have expected, perhaps because the rigour of systematically following the steps in IPA facilitates adherence to its idiographic commitment and the treatment of each case on its own terms (Smith, Flowers and Larkin, 2009).  The outcome, therefore, was the creation of five more tables of themes, one for each domain of enquiry, in respect of my second case.  Having completed this latter exercise, I moved to my third and fourth cases, respectively, essentially repeating the process, as outlined and producing ten additional tables of themes, five per case.

### 3.14   Ethics

Prior to the commencement of my research, I submitted an application for ethical approval for my study to the Humanities and Social Sciences (HaSS) Faculty Ethics Committee of the University (Appendix J, p. 155).  This ethics application, accepted without amendment, outlined the following: my project title and type, my research question, the format and aims of the study,

the methodology, participants' details, information regarding consent, debriefing, insurance and risk considerations.  It also included the supporting documents.

Upon receipt of the requisite approval, I began my research. I spoke to the parents of the participants and explained to them that participation was voluntary, that their children would not be identified in any way in my report, that I would speak to the children alone in their homes whilst at least one parent was present in an adjoining room and that our conversations would be tape-recorded. They were also given a Participant Information Sheet (Appendix D, p. 149), which I asked them to discuss with their children and Consent Forms (Appendices E and F, pp. 150 - 151).

Each interview was recorded on two small Olympus Digital Voice Recorders (to ensure full audio coverage of my interactions).  Following the interview, each child was provided with an individual debriefing session and a Debriefing Sheet (Appendix G p. 152).  The Debriefing Sheet summarised, in simple language, the general aims and scope of the study.  It highlighted the significance of the children's contributions and my appreciation in respect of same.  A key objective was to include my contact details in the event that any child wished to get in touch with me, following our meeting, either because feeling uneasy or in need of additional information.  It concluded with an expression of thanks to the children's parents.  Finally, the parents were invited to join in the discussion.

The recordings were transcribed onto my password-protected computer and then printed on sheets of paper for analysis. They were stored under lock and key in a secure location in my home. The recordings will be deleted and the transcripts will be destroyed at the end of the research.

# Chapter 4. Findings - Presentation

## 4.1 Introduction

In this chapter, I provide an overview of my findings in relation to my research questions and associated domains of enquiry. This takes the form, initially, of a series of five Master Tables of themes, each corresponding to a particular research question and domain: Tables 1 – 5 below. I then present a series of tables which include quotations illustrative of all identified themes and which will provide the reader with a flavour of the content in every instance: Tables 6 – 10 below. Finally, I examine each theme in detail, describing my findings in relation to the interview questions posed as part of each domain: Questions 1 – 24 (Appendix C, pp. 147 - 148).

The aim of my research was to explore the identity construction of four school-going children having a diagnosis of CF with a view to establishing whether or not they consider themselves to be disabled and to have a disability. The question motivating this study, therefore, is: What kind of identity are children with CF constructing as they make their way through school?

In attempting this task, I drew on five domains of enquiry, devising a single question to capture the essence of each in turn and to guide my work. These five questions form the basis of this thesis and the findings they generate help answer my overarching question as stated above.

The research questions and domains being explored in this study were as follows:

*Research Question 1:* What is CF and how does it affect you?
*Domain 1:* What CF means to the Children

*Research Question 2:* Who are you and why do you say you are who you say you are?
*Domain 2:* The Impact of CF on the Children's Sense of Self

*Research Question 3:* How does CF affect your school life and others' perceptions of you?
*Domain 3:* The Impact of CF on the Children's School Life

*Research Question 4:* What does the future mean to you?

*Domain 4:* The Impact of CF on the Children's Sense of the Future


*Research Question 5:* How is life for you?

*Domain 5:* The Impact of CF on the Children's Sense of Life in General

## 4.2 Master Tables of Themes


The tables presented in this section (Tables 4.1 – 4.5) reveal the constituent themes discovered in respect of the research questions and domains outlined above. Each research question generated a number of interview questions, this number ranging from two to eight. In all, a total of 24 questions comprised the Interview Schedule, which is reproduced in Appendix C, pp. 147 - 148. Interview questions are not included in the tables below.


The constituent themes emerged, for the most part, either in the younger (aged 11 and 13) or in the older (aged 16) children's accounts. Accordingly and where relevant, the label EA (Early Adolescence) is used to signify the responses of the two youngest participants and the label LA (Late Adolescence) accompanies the responses of the two oldest participants. It must be stated, at this juncture, that some of the themes discovered may equally apply to children not having CF, but there is insufficient evidence to explore such matters.


*Research Question 1:* What is CF and how does it affect you?

*Domain 1:* What CF means to the Children


| Interview Questions | Constituent Themes |
| --- | --- |
| Q 1 | LA: being scared |
| | EA: a burden |
| Q 2 | LA: a routine |
| | EA: a nuisance |

**Table 4.1.** Constituent Themes for Research Question 1.
(What is CF and how does it affect you?)

*Research Question 2:* Who are you and why do you say you are who you say you are?

*Domain 2:* The Impact of CF on the Children's Sense of Self

| Interview Questions | Constituent Themes |
|---|---|
| Q 3 | Being sporty & physically active |
| Q 4 | Being different |
| Q 5 | Being supported |
| Q 6 | Having experiences & interests |

**Table 4.2.**     Constituent Themes for Research Question 2.
                   (Who are you and why do you say you are who you say you are?)

*Research Question 3:* How does CF affect your school life and others' perceptions of you?

*Domain 3:* The Impact of CF on the Children's School Life

| Interview Questions | Constituent Themes |
|---|---|
| Q 7 | LA: considerable disruption |
|  | EA: little disruption |
| Q 8 | LA: having everything under control |
|  | EA: reduction of embarrassment |
| Q 9 | LA: managing with help of friends |
|  | EA: compliance with CF regimen |
| Q 10 | LA: uncertainty but contentment |
|  | EA: uncertainty |
| Q 11 | LA: behaviour in school |
|  | EA: strengths & weaknesses |
| Q 12 | LA: opinions formed/decisions made |
|  | EA: discussion as problematic |
| Q 13 | Gateway to achievement of goals |

**Table 4.3.**     Constituent Themes for Research Question 3.
                   (How does CF affect your school life and others' perceptions of you?)

*Research Question 4:* What does the future mean to you?

*Domain 4:* The Impact of CF on the Children's Sense of the Future

| Interview Questions | Constituent Themes |
|---|---|
| Q 14 | LA: the generic self |
|  | EA: specific careers |
| Q 15 | LA: coping with challenge |
|  | EA: an educational process |
| Q 16 | LA: collective strength |
|  | EA: lack of commitment |

| Q 17 | LA: exploration |
| | EA: lack of exploration |
| Q 18 | LA: being vulnerable |
| | EA: being cautious |
| Q 19 | LA: being strategic |
| | EA: being ambivalent |
| Q 20 | LA: proximity |
| | EA: distance |
| Q 21 | LA: achievement |
| | EA: happiness |

**Table 4.4.**    Constituent Themes for Research Question 4.
(What does the future mean to you?)


*Research Question 5:* How is life for you?

*Domain 5:* The Impact of CF on the Children's Sense of Life in General

| Interview Questions | Constituent Themes |
| --- | --- |
| Q 22 | LA: appreciation |
| | EA: acknowledgement |
| Q 23 | LA: CF status |
| | EA: lack of enthusiasm |
| Q 24 | LA: being free of CF |
| | EA: acceptance |

**Table 4.5.**    Constituent Themes for Research Question 5.
(How is life for you?)


## 4.3    Tables of Example Quotations


The tables which follow (Tables 4.6 - 4.10) present example quotations for each constituent theme.  The aim is to help the reader to develop a sense of the type of material discovered in relation to each research question and of the range of ideas provided by the children. In selecting quotations, I focused on the appropriateness and succinctness of the responses as distinct from issues such as frequency of occurrence in the transcripts or equality of representation across the participant sample.


For ease of reference, I also provide, below, details of the children's pseudonyms and ages as originally presented in the methodology section (Table 3.1, p. 43). Pseudonyms have also been used for all other individuals and for the locations named in this study.

| Children's Pseudonyms | Children's Ages |
|---|---|
| Participant 1: Therese | 16 years |
| Participant 2: Pauline | 16 years |
| Participant 3: Celine | 13 years |
| Participant 4: Louis | 11 years |

**Table 3.1.** Children's Pseudonyms and Ages *(Reproduced here from p. 43)*

| Constituent Themes | Example Quotations |
|---|---|
| LA: being scared but agentic | Therese: 'I'm kinda scared to see what's said ... I don't want to ... hear somebody's stories about life expectancy and stuff... I want to figure it out for myself.' |
| EA: a burden | Celine: 'You have to remember to take your tablets ... you have to exercise and ... mind what you're eating and ... do your physio.' |
| LA: a routine | Pauline: 'It's gone into a routine ... I'll take my inhalers, then I'll get my breakfast, then I'll take whatever tablets I have to ... It's just ... something I've just got used to doing.' |
| EA: a nuisance | Louis: 'I have to ... take half an hour of my day doing my inhaler thing.' |

**Table 4.6** What is CF and how does it affect you?

| Constituent Themes | Example Quotations |
|---|---|
| Being sporty & physically active | Louis: 'I play rugby ... I love sailing as well and I do taiquando.' |
| Being different | Louis: 'I like to see myself just as someone kind of normal ... I know I have CF but I try to be as kind of as normal as possible.' |
| Being supported | Therese: 'My family ... have been there for me through everything ... without them I don't think I'd get through as much as I have... My friends ... have been there for me from day one ... I'd be lost without them.' |
| Having experiences & interests | Pauline: 'I've always had a sport I've been doing ... and then ... I just kind of ... know how to play on the laptop and ... on the computer.' |

**Table 4.7** Who are you and why do you say you are who you say you are?

| Constituent Themes | Example Quotations |
|---|---|
| LA: considerable disruption | Pauline: 'When I ... get sick ... I can miss a lot of time off school, then ... I'm trying to catch up ... in second year ... I missed so much school and in transition year ... I was in hospital as well so I missed so much school then too.' |
| EA: little disruption | Louis: 'No ... sometimes ... like ... going into hospitals and stuff ... for a check-up or something ... it doesn't really affect me that much.' |

| | |
|---|---|
| LA: having everything under control | Therese: 'I've no problems with getting to classes ... If I had a problem I'd ask a teacher and they'd help out ... if I miss school ... there's teachers in the hospital that I talk to ... I ... try catch up on notes from ... the [local] teachers ... so it's grand.' |
| EA: reduction of embarrassment | Celine: 'In the school ... we're not allowed take off our jumpers ... but ... I'm allowed ... and ... this fella in our class keeps asking can he take off his jumper and then the teacher says no to him ... and ... they'd be kind of wondering why I take it off then.' |
| LA: managing with the help of friends | Pauline: 'They all have an inhaler of mine in their bags and ... tablets ... I ... ask the girls what I missed ... I ... get notes off them and ... I find a way around it ... it's not ... a ... big deal.' |
| EA: compliance with CF regimen | Louis: 'I try to take my medication ... so I don't kind of feel rough or feel sick.' |
| LA: uncertainty but contentment | Therese: 'I wouldn't really know what way people see me ... in general I think they look at me differently ... but a lot of people see me as just a normal person so ... it's grand ... I'm a happy person because I have family and friends who're there for me all the time.' |
| EA: uncertainty | Celine: 'Well I'm not too sure in secondary school ... I know in primary school ... my friends are always saying ... how can you be so nice.' |
| LA: behaviour in school | Pauline: 'It's just the way I am. Like I don't act as if there's something wrong ... as if I've a big problem ... I'm just acting myself and act normal as if I don't have it.' |
| EA: strengths & weaknesses | Louis: 'I really am into my sport. Everything I talk about is sport ... in the Irish I'm not very good 'cause I ... missed out ... a bit.' |
| LA: opinions formed/decisions made | Therese: 'They're going to judge you whether you do stuff or don't do stuff ... so what way they see me doesn't really bother me ... once I have [my friends and family] I don't really care what other people think.' |
| EA: discussion as problematic | Louis: 'I don't really want to ... go off explaining it [CF] to them ... I ... say I have CF and it affects ... my tummy and so I have to take pills and things. That's all ... I don't make too much of it.' |
| Gateway to achievement of goals | Therese: 'Cause I want to do well ... in the end I want to have a future and I want to have a job and I want to have a family.' |

**Table 4.8.**      How does CF affect your school life and others' perceptions of you?

| Constituent Themes | Example Quotations |
|---|---|
| LA: the generic self | Pauline: 'I want to go to college ... I want to have a good job and I want to be able to do ... well ... I want to be healthy ... and be well.' |
| EA: specific careers | Celine: 'I would like to be a hairdresser and a make-up artist.' |
| LA: coping with challenge | Therese: 'Just try and study and ... get a good Leaving Cert ... I know ... I'm going to have so many admissions [hospitalizations for IVs] ... I'm so stressed out ... Knowing that I'm missing school is making me ten times |

| | worse ... it's hard like. When I come home from school ... I'm just wrecked tired and ... I don't even feel like eating.' |
|---|---|
| EA: an educational process | Louis: 'I'm hoping I'm going to a really good secondary school ... that has a good reputation ... And ... do things I really like there ... and I kind of need teachers to help as well ... to ... tell me ... stuff.' |
| LA: collective strength | Therese: 'With people that care about me ... they're going to help me get through things and to succeed.' |
| EA: lack of commitment | Celine: 'When I get older ... when I get to my Leaving Cert ... what I want to do will probably change.' |
| LA: exploration | Pauline: 'It's something I like doing ... when I was doing work in summer I learned more about what I was doing ... so I ... just set my goals ... then.' |
| EA: lack of exploration | Louis: 'An architect ... I just love ... building stuff ... and I like ... drawing ... maps and ... pictures of boats and cars'. |
| LA: being vulnerable | Therese: 'I've thought of so many different things but ... when I got really sick ... last Christmas ... that took a lot out of me ... that scared me a lot ... I think ... I'd just keep trying ... until I got where I wanted to go.' |
| EA: being cautious | Celine: 'But ... I'm ... happy ... I'll think of something ... [and quoting from a friend's card, she added] ... forget the future you can't predict it.' |
| LA: being strategic | Therese: 'I don't really like thinking about the future in that [i.e., CF] context ... because then I'd just bring myself down ... because a lot of people say ... the older you get the worse it gets ... [but] ... I think about school' |
| EA: being ambivalent | Louis: 'Occasionally ... at school we ... talk quite a lot ... about the future, kind of, so ... yeah ... I do think about it ... definitely.' |
| LA: proximity | Therese: 'I'd say about 5 years ... [when] ... I'm going to be in college.' |
| EA: distance | Celine: 'When I'm kind of old and ... I ... have that job.' |
| LA: achievement | Pauline: 'I want to be able to do well and have a good life.' |
| EA: happiness | Celine: 'That I enjoy it anyway ... just ... enjoy it.' |

**Table 4.9.**      What does the future mean to you?


| Constituent Themes | Example Quotations |
|---|---|
| LA: appreciation | Pauline: 'I've a really good family ... They're always there. And then my nanny and granddad ... they're brilliant ... they're always there as well. My friends as well ... I just, I love them ... they're so good and we're all so close.' |
| EA: acknowledgement | Celine: 'I've good friends. My family. I ... enjoy life ... I like my hospital. They're good ... and ... my nurses are nice.' |
| LA: CF status | Pauline: 'I wish I didn't have CF ... It really is a pain to have |

| | but ... you have to just deal with it.' |
|---|---|
| EA: lack of enthusiasm | Celine: 'People are saying that there's a drug out for one gene of Cystic Fibrosis but ...it doesn't really make a difference ... I don't really ... think about having it. I just ... get on with it.' |
| LA: being free of CF | Therese: 'My wish ... that there would be no illnesses ... at all ... not just CF like, in general ... just none ... at all.' |
| EA: acceptance | Louis: 'Well, I think it's ... okay having it [CF]. I mean it's kind of annoying sometimes ... but otherwise ... everything's kind of fine ... it doesn't really affect me [much].' |

**Table 4.10.**     How is life for you?


I now present details of all the themes discovered in the participants' responses to the interview questions posed as part of each domain of enquiry (Questions 1 – 24; Appendix C, pp. 147 - 148) with the caveat, as noted above, that some of these themes may equally apply to children not having CF.

## 4.4   Research Questions and Domains

### 4.4.1   Research Question 1: What is CF and how does it affect you?

Research Question 1 was designed to guide exploration of the first domain of enquiry: what CF means to the children.  This exploration required the construction of two interview questions: Questions 1 and 2.  I will examine each of these questions separately and in sequence, below.

Questions 1 and 2 each generated two themes: one representing that produced by the youngest participants and labeled EA and one representing that produced by the oldest participants and labeled LA.  I will deal, firstly, with the responses produced by the youngest participants (EA) and then proceed to those produced by the oldest participants (LA).

**Question 1:  Tell me what you think CF is.**
 [EA]
To the younger children, CF is a burden which they bear because they have no choice – if they do not do certain things on a regular basis they will not be well.  For Louis this essentially involves taking medication, exercising and watching his diet: *'I know if I don't take my pills and I don't kind of exercise enough and eat enough and stuff I know I won't be well, I know I won't be*

*healthy'* (P4, 5).  For Celine, there is all of the above, plus the additional burden of physiotherapy, a theme to which she frequently returns.

[LA]

The older children claimed not to really know what CF is but admitted to not wanting to know.  Therese put it as follows: *'I tend ... not really to ask questions.  I don't really want to know ... the logics and the theories about CF'* (P1, 12).  Pauline had a similar approach: *'I've always kind of just known the bare minimum about it'* (P2, 6).  Both had looked into it, albeit in cursory fashion, at some point however, but hadn't pursued such research.  Therese adopted an unapologetic stance: *'I've never really properly read up on what CF is ... even on the internet'* (P1, 12).  Pauline was decisive: *'there's times like I've looked up stuff about it ... I don't find out more ... [though] ... I could'* (P2, 6).  It would appear that the limited information that they have gleaned in relation to CF has simply scared them and discouraged them from pursuit of further information.  For Therese, the specifics to be avoided seem to relate, in particular, to the critical issue of life expectancy and all that it entails: *'I think I'm kinda scared to see what's said ... I don't' want to ... hear somebody's stories about life expectancy and stuff ... I don't' want to know because then I'd be living maybe like, ah, ...'* (P1, 12). Their strategy for handling CF it is to deal with difficulties as they occur.  In this regard, Therese has very definitely resolved to take matters into her own hands: *'I kinda just want to see for myself, day by day, like, for me.  I just ... I don't want to be told this, that and the other ... I want to figure it out for myself'* (P1, 12).  In contrast, Pauline, while effectively adopting the same general approach, credits this practice to her mother: *'The way my mam has kind of done it's whatever is happening me, whatever I have, it's just the way I deal with it'* (P2, 6).  For both participants, CF is certainly a challenge.   It appears to represent something quite negative for Pauline: *'It's ... just ... a horrible illness people get'* (P2, 6).  Therese, however, seems more accepting: *'To me, it's basically ... it's just a part of life to me.  Like I wouldn't ... I don't see it as a disease ... I just see it as I have something that someone else doesn't'* (P1, 12).

**Question 2:  How does CF affect you from day to day?**

 [EA]

The concept of CF as a nuisance emerged in the responses of the early adolescents to the question of its impact on their daily lives.  In the case of Celine, the physiotherapy issue emerged once more, this time in the context of tiredness: *'Well ... sometimes I'd be tired and I wouldn't really*

*like to do my physio, I know I have to but you know I'd be tired'* (P3, 6).  Clearly, the difficulty surrounding her physiotherapy regime is non-medical and more akin to an irritation than to a serious problem: *'I'm not the best to get up and then sometimes you know you've to try and get up earlier to do it and stuff ... [because] ... you can't be missing it'* (P3, 7).  For Louis, the annoyance relates to the fact that he has to make time each day to take his inhaler: *'I have to ... take half an hour of my day doing my inhaler thing'* (P4, 6).  In addition, he has to continuously watch his weight: *'Yeh, it kind of affects the way I eat, because I have to eat a bit more because I kind of have to put on weight usually'* (P4, 6).  However, shortly before our meeting he had discovered another complication:*'I had to stop eating sugar for a bit'* (P4, 6).  Again, his difficulties appear more bothersome than severe.

[LA]

The impact of CF on the daily lives of the late adolescents was revealed to be considerable.  Nevertheless, the treatment schedules outlined in the responses of both participants were suggestive of a set of procedures which had become relatively routine.  Therese put it as follows: *'Normally for school ... a lot of my friends ... get up at about eight and then they'd be ready for about half eight and school's at nine.  But I'd have to get up at six o'clock and ... start my nebs.'* (P1, 13).  She continued: *'And then I start the rest of my nebs at seven.  I have to do pyhsio in the morning ... as well.  Then I do vitamins and ... especially like if there's IVs on top of that, if I'm sick and I have to take IVs, that's another plus and then I get out for school'* (P1, 13).  She calculated: *'So in all it would take about two hours to get everything done in the morning'* (P1, 13).  The treatment schedule has to be continued during school hours: *'During the school day I bring my inhaler with me ... [and] ... I'd have my creon with me to take during eating food and stuff'* (P1, 14).  There are additional treatments after school: *'And then after school, at four o'clock, I'd come home and ... I'd be straight into my nebs and physio'* (P1, 13).  She made another calculation: *' ... when I come home it's basically an hour again taking nebs and doing physio'* (P1, 14).  The treatments end at bed-time: *'And then before I go to bed more nebs and more physio.  Em, before going to bed it would be about another hour basically ...'* (P1, 14).  While confirming that spending approximately four hours each day on her treatments is not easy, Therese brought her response to a close like this: *'It's like getting up and brushing your teeth ... it just comes naturally'* (P1, 15).  Pauline revealed a similar experience and sentiment:  *'It's gone into a routine ... I'll take my inhalers, then I'll get my breakfast, then I'll take whatever tablets I have to ... It's just ... something I've just got used to doing ...'* (P2, 7).

### 4.4.2  Research Question 2: Who are you and why do you say you are who you say you are?

Research Question 2 was designed to guide exploration of the second domain of enquiry: the impact of CF on the children's sense of self.  This exploration required the construction of four interview questions: Questions 3 - 6.  I will examine each of these questions separately and in sequence, below.

Questions 3 through to 6 each generated but one theme.

Reminder: these questions were put to the children at the start of their interviews, i.e., before those outlined above – see Methodology chapter, pp. 43 – 45.

**Question 3:  Tell me a little about yourself**

This question, the first to be asked, was designed to function as an uncomplicated icebreaker which would not only provide me with certain information about the children but which would also facilitate the establishment of some rapport between us at the outset.  In this regard, it proved to be a successful choice.  The children willingly supplied me with details regarding their full names, dates of birth, addresses and schools, data which cannot be reproduced here due to the confidentiality and anonymity guaranteed to all participants and their families.  However, they also provided additional details which can be revealed.  Therese, for example, talked about a long period of ill health which had begun approximately nine months prior to our meeting but which was almost over: *'I was really sick over last Christmas … last year, I think it was coming into January, I got the swine flu and I ended up catching pneumonia on top of it so I was really sick but ... I came out of it and I'm nearly back to my old self again'* (P1, 2).  She was the only subject to mention her health status at this point in time.  Celine, uniquely, raised her love of animals*: 'I like horses and dogs'* (P3, 1); *'I like animals'* (P3, 2).

The theme shared by all the participants was that of physical activity.  Clearly, being sporty and active is an important part of their lived experiences.  A variety of activities was mentioned.  Louis illustrated this as follows: *'I play rugby  … I love sailing as well and I do taiquando'* (P4, 1).  Pauline revealed a love of and an aptitude for swimming: *'I really love swimming.  I used to swim for Northumberland and everything.  I used to do the community games'* (P2, 4).  She also

likes *'exercising'* and stated: *'I've got my gym membership now so I'm always at the gym now as well'* (P2, 2). For Celine it was Gaelic sport: *'hurling and camogie'* (P3, 1). Therese enjoys dancing: *'I dance ... I do a lot of dancing'* (P1, 1) and being out-of-doors generally, especially in summer-time: *'Normally like the summer I'd be out 24/7'* (P1, 2).

**Question 4: How would you describe yourself as you really are now, as you see yourself now?**

The children approached this question in a variety of ways but, in every case, the theme of difference emerged in their responses. For example, Therese and Pauline began by describing themselves as happy: *'I'm a happy person'* (P1, 3); *'I just am happy and friendly'* (P2, 2). However, Therese immediately launched into the fact that she has issues to deal with: *'you know a lot of things go on ... I deal with a lot of stuff'* (P1, 3). Her approach to such matters is to *'always act just like a normal person'* (P1, 3). She went on to say that even a conversation with another child having CF would *'more or less be the same as with a normal person. It wouldn't be any different. It would just be ... general topics'* (P1, 6). Pauline proceeded to portray her situation as not being different to that of others: *'I wouldn't think of it as being different 'cause I don't really know any different'* (P2, 7). She explained: *'even when I was a child, I never thought of it as being weird or different'* (P2, 8). In this context, she referred to her obligation to regularly take medication: *'I've always known to take my tablets when I'm eating ... just to do my meds. I never really thought of it as anything different'* (P2, 8).

The younger children displayed a remarkably similar approach to this question. Celine started off by saying that she likes company: *'I like being with my friends. I don't really like being just ... by myself'* (P3, 2). Nevertheless, she eventually confided the following, unprompted: '*I just like kinda just like just be normal kinda'* (P3, 12). For her, having to work hard to get the mucous from her lungs appears to separate her out from people not having CF: *'We need to do physio ... to try and get it up ... the other people can just get it up'* (P3, 5). Louis, rather confidently, described himself, initially, thus: *'I'm a perfectionist really 'cause I like things done quite properly'* (P4, 2). Then, on reflection, he added: *'I like to see myself just as someone kind of normal ... I know I have CF but I try to be as kind of as normal as possible'* (P4, 2). He explained: *'I don't try to hide it but ...'* (P4, 2). He suggested: '*if I do all that stuff ... [take his medication, etc.] ... I'll just be a normal person really'* (P4, 5).

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**Question 5:  How have you managed to become this person?**

The dominant theme in the children's responses to this question was that of support.  In every case, they willingly attributed their current status to their families in the first instance.  As Therese put it: *'My family ... have been there for me through everything.  We're such a close family ... without them I don't think I'd get through as much as I have'* (P1, 6).  In Pauline's case, she readily identified her mother as a key figure in her support structure: *'my mam is always pushing me ... when I used to do swimming ... [competitively] ... my mam would push me to do it'* (P2, 4).  Pauline also identified her mother's partner as a significant source of encouragement in relation to another of her strengths: working with computers.  She elaborated thus: *'Anthony was just like you're actually really good at this and so it's kind of ... gone from there'* (P2, 4).  For Celine, it is her mother's determination to get her to do her homework quickly that she actually appreciates: *'luckily tonight we don't have that much homework but usually nights ... I'd be nearly there all evening unless mam told me to get out [and make time for other pursuits]'* (P3, 14).  Louis simply stated: *'Well, I have a nice home and nice family'* (P4, 3).

The role played by their friends was also acknowledged, at this juncture, by two of the children: Therese – *'My friends ... have been there for me from day one ... I'd be lost without them'* (P1, 6); Louis – *'Yeah ... I'm helped ... [by] ... really nice friends'* (P4, 3).

**Question 6:  Why do you think you are as you say you really are now?**

This question revealed an acknowledgement on the part of the children that their experiences and interests contributed to their current identity, but it also revealed a variety of analytic approaches to the issue.  This ranged from avoidance of any reference to CF as a factor to complete acceptance of CF as having a role.  Louis, for example, talked about his experience of living abroad as making a difference:  *'Yeah ... kind of moving to Germany and leaving Argentina and stuff ... that would have changed me a bit ...'* (P4, 4).  He also, however, returned to his belief about his perfectionism, attributing at least part of the reason for his stance in this regard to the feedback he receives from his friends: *'my friends quite often say, I mean not like in a teasing way but they just say you really like things done properly'* (P4, 3).

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Celine also avoided specific mention of CF but talked about one of its effects and about the obligation to deal with this: *'Well ... you have to do your physio practice. You've to do that or else you'll get sick'* (P3, 3). While not directly articulating a health issue, she recognises that she is as she currently is because she adheres to her physiotherapy regime. She considers this to be of great consequence, so much so that she reveals a certain annoyance about the fact that this is not generally recognised: *'those programmes on TV ... they don't really stress about how important the physio is'* (P3, 3). She seems to suggest, as well, that she is a nice person, but that the reason may be more strategic than authentic: *'Am ... you know that if you're not nice to others they won't be nice to you either'* (P3, 3).

Pauline focused on her interests as the reason why she is as she says she is now. In this regard, she highlighted her interest in sport, particularly swimming and in computers: *'I've always had a sport I've been doing ... but swimming's always been the number one sport I've always done ... and then ... the computer ... I just kind of ... know how to play on the laptop and ... on the computer'* (P2, 5). Finally, she admits that in describing herself, she refrains from any mention of CF: *'It's not something I'd ... say about me ... it's not the way I'd describe myself'* (P2, 5).

Therese, on the other hand, begins her response by linking her medical condition with her current identity: '*CF is kind of a part of me and it's made me who I am. Like if I didn't have my CF ... I'd say I'd probably be a different person'* (P1, 11). She considers that her CF – related experiences, while difficult, have actually enabled her to develop personal strength: *'I think after going through everything, from admissions in and things I've done with my life ... through the experiences and just meeting new people ... I think myself I've become such a stronger person'* (P1, 11). She goes on to explain what she means by this: *'Like more drive ... to succeed. I want to do things for myself much more than I would I'd say if I didn't' have CF'* (P1, 11). Her motivation is also clarified: *'I think I just want to prove to people that I can do things that they can do. Eventhough I have CF, it's not going to hold me back'* (P1, 11).

### *4.4.3   Research Question 3: How does CF affect your school life and others' perceptions of you?*

Research Question 3 was designed to guide exploration of the third domain of enquiry: the impact of CF on the children's school life. This exploration required the construction of seven

interview questions: Questions 7 - 13.  These questions covered such topics as: the difference it makes; how their experiences could be improved; the school community's perceptions of them; their feelings regarding their situation and the importance of school to them.  Again, I will examine each of these questions separately and in sequence, below.

Questions 7 through to 12 each generated two themes: one representing that produced by the early adolescents and one representing that produced by the late adolescents.  As above, I will deal, firstly, with the responses produced by the youngest participants (EA) and then proceed to those produced by the oldest participants (LA).  Question 13, which generated but one theme, will be dealt with in similar fashion to Questions 3 through to 6 above.

**Question 7:  Does having CF make a difference at school?**

 [EA]

The early adolescents were reluctant to respond either positively or negatively to this question.  Celine, for example, initially said *'Not really'* largely because of her experience at primary level which had been unproblematic: *'in primary school people just know you have CF and they just know you take tablets ... they're kinda used to you, if you know what I mean'* (P3, 7).  She seemed to suggest that the important element for her was not having to explain her actions: *'in primary school nobody would really ask you what are they ... [the tablets]'* (P3, 8).  Moreover, *'You're not gonna say, that's kinda like presume you know'* (P3, 8).  Her difficulty at the time of our meeting, however, was that she had just transitioned into the second level system and begun attending a new school where things were different.  With regard to the issue of taking tablets at lunch-time, her problem now was that *'some people would be saying why, what are they, you know'* (P3, 7).

Louis was still in the primary system and, like Celine, seemed not to be experiencing any real difficulties at school.  However, he had to think a great deal about his reply and then appeared to contradict his initial reaction:  *'No ... (long pause) ... No ... sometimes ... like ... going into hospitals and stuff'* (P4, 7).  He then confirmed that from time to time he has to miss school due to having to *'go in for a check-up or something'* (P4, 7).  In this context, he admitted that having CF makes a difference in that, being absent, he wouldn't be able to do his homework: *'Well I ... wouldn't take down the homework or something 'cause I wouldn't be there'* (P4, 7).

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Nevertheless, he was disinclined to admit to having difficulites and concluded by saying that *'it doesn't really affect me that much'* (P4, 7).

[LA]

The older children were clear that having CF makes a difference at school. Therese responded positively to this question, as follows: *'Yeah. It does. I find even especially this year a lot more so than previous years because this year I'm in fifth year and it's a lot of going and new subjects and stuff'* (P1, 16). In this context, fatigue and absenteeism due to CF can be problematic: *'I find ... I'd be very tired ... and ... trying not to fall behind when missing days ... be hard'* (P1, 17). For Pauliine, the level of disruption that she has had to endure, at various stages, while in the second level system, seemed almost to exasperate her: *'when I ... get sick ... I can miss a lot of time off school, then ... when I'm trying to catch up it's just like ... it's a pain and it's annoying ... in second year ... I missed so much school and in transition year ... I was in hospital as well so I missed so much school then too ...'* (P2, 8).

Both participants referred to their classmates in attempting to respond to this question, but their references revealed somewhat different experiences and relationships. In the case of Pauline, for example, enforced absences irritate her not just because of the detrimental effect on her scholastic progress but also because of the associated interruption in activities with friends: *'not being able to do things with my friends if I'm sick or if there's something with me'* (P2, 9). However, it would appear that when she is too sick to attend school her friends visit her: *'my friends are so good like ... if there's something wrong they'll come down to me, they'll stay with me ... after school ... they'll make sure I'm okay'* (P2, 9). In this way, while unable to partake in activities with them, she nevertheless maintains physical contact with them. Such contact necessitates disclosure of at least some information regarding her medical condition: *'they've been here the nights I've been sick and nights they've seen when there's been horrible things wrong with me and when I've had my drips in ... they've always been here'* (P2, 9).

Therese, on the other hand, appears to have a different attitude towards the disruption which her CF causes and a different relationship with her school friends. Firstly, she never talks to them about being unwell and having to miss school as a result: *'I'd never talk about being sick ... I just ... [say] ... I'm not going in today'* (P1, 19). However, she says that being absent signals to them that she is actually not well enough to attend: *'If I was sick and out of school, people would*

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*automatically think oh, she's sick'* (P1, 19).  In such situations, she keeps in touch with them via electronic devices: *'I talk to a lot of the girls through facebook and texting ... if I wasn't in ... I'd still keep in contact with them'* (P1, 17).  Their conversations, however, do not include talk about CF: *'Not many of my friends would actually bring up CF ... unless I was talking about something, which I don't ... I never really talk about my CF ... with anyone'* (P1, 18).  She maintains this stance eventhough she suspects that most of her friends know that she has CF and lack knowledge of the condition: *'I think a lot of people know I have CF but they don't really know what exactly it is'* (P1, 19).  This may explain why, following initial placement of her current class in a room which was found, belatedly, by the school authorities, to be unsuitable for Therese and the subsequent transfer of the class to a more appropriate room, causing considerable disruption for everybody, her friends failed to understand the reason for the change: *'the girls were like why are we moving now'* (P1, 16).  The teachers did not clarify the situation either: *'the teachers [were] just like oh because you have to'* (P1, 16).  Therese found this embarrassing: *'I'm just sitting there and I'm like oh great ...'* (P1, 16).  However, she does not like being reminded about her CF, even by close friends, during school: *'My friend Helena ... her cousin Margaret had Cystic Fibrosis ... I was actually quite close with Margaret ... but Margaret passed away ... last Christmas so that was ... quite hard, but ... Helena would always bring up comments ... and if Helena sees me with ... a box of creon ... she'd be like ah still remember Margaret taking them, do you know ... like things like that ... and it's just ... ah! ...'* (P1, 18).  She continued: *'Ah, for me it was really hard.  It was hard like.  Just ... it still is ... to think like about her'* (P1, 18).

**Question 8:  What would make things better for you at school?**

[EA]

The younger children were a little coy on the subject of what might make things better for them at school.  In both cases, however, the theme which emerged was embarrassment reduction.  For Louis, this related to his problem with the Irish language which was a particular concern: *'Well, if we didn't have to do Irish ... [giggle] ...'* (P4, 8).  His discomfiture in articulating this was evident.  Celine responded with the following statement: *'There's not really a lot would make things better'* (P3, 10).  Then she outlined a specific predicament: *'in the school ... we're not allowed take off our jumpers ... but ... I'm allowed ... and ... this fella in our class keeps asking can he take off his jumper and then the teacher says no to him ... and then I take it off'* (P3, 10).  Her dilemma appears to be related to the effect this is having on the other children: *'they'd be kind of wondering why I take it off then'* (P3, 10).  Her solution is that *'it would be better if they*

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*were all allowed just take off their jumpers'* (P3, 10).  With regard to whether or not anyone had said anything to her about this, she replied: *'No.  Nobody has'* (P3, 11).  Again, not having to discuss the matter seems to be a relief to her: *'Well … I don't really mind'* (P3, 11).

[LA]

The responses of the late adolescents revealed a view which suggested that, in the circumstances, everything was under control. For Pauline, the issue is having CF; not having it would make things better for her at school: *'I don't like being sick all the time and I wish there was something I could do to prevent that but I can't, it just happens, if I'm sick I'm sick and I have to miss time off school and I have to get better'* (P2, 11).  She then added: *'I get grinds* [extra tuition, usually provided outside classtime for a fee] *and that'* (P2, 11).  In this regard, she communicated a certain defensiveness: *'But there's a lot of girls that get that as well.  I don't feel … it's because … [of having CF]'* (P2, 12).  However, the central message was that her needs were being met: *'I need it too so and it's better then if I miss it [school] that … I know I've got help'* (P2, 12).  The concept of seeking other forms of assistance had not occurred to her: *'I've never really thought about that'* (P2, 12).

Therese was equally content about her current educational service: *'to be honest I think I'm quite happy with the school … the teachers and everything … they're great and the principal and my vice principal.  They're just so good to me'* (P1, 19).  She added the following observations: *'I've no problems with getting to classes and that because most of my classes are actually in the same place … And if not, the lab that I have to go to for science or something … that's literally … across the hall … I don't have problems like'* (P1, 20).  Her strategy in the event of a problem occurring was clear and apparently effective: *'If I had a problem I'd ask a teacher and they'd help out'* (P1, 20).  In this regard, the exemplar she provided related to the type of problem she encounters due to absences: *'if I miss school there's teachers in the hospital that I talk to … I try catch up on notes from … the [local] teachers'* (P1, 21).  She explained: *'the last time I was in … we were studying Macbeth … I was going through summary notes and stuff … with the teacher and she said to me would it be okay if I contact your school and I said 'yeah … it would be great'…'* (P1, 23).  That was a positive experience: *'I found it quite good'* (P1, 23).  While admitting that communication between the teachers in the hospital school and her own local school had been negligible *'up until this year'* (P1, 21), she was eager to state that *'they said next year they'll keep in contact with the school from the hospital because of it being 5th and 6th year'*

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(P1, 21).  Moreover, she continued: *'They're actually offering [to do this] ... so it's grand'* (P1, 21).  The issue of enhanced communication between both sets of teachers was not something that she wished to discuss: *'See, I don't want [the local] teachers to treat me differently because I'm sick'* (P1, 22).  For this reason, she is happy with the status quo: *'So in a way I'm kinda glad the way it's being done now, because I want to be treated like everyone else ... Oh, she's sick ... take it easy on her.  I don't want that'* (P1, 22).  She added: *'I think the teachers know that 'cause I don't let them be easy on me'* (P1, 22).  In similar vein, the issue of enhanced knowledge in respect of CF among her classmates is problematic: *'I don't really know ... I suppose for them it would be a good thing to know about CF but then I wouldn't like to be treated differently by them ... when they know what CF is'* (P1, 23).  Her own knowledge, or lack of same, regarding CF further complicates matters: *'And I don't really know for sure exactly ... what CF is but I don't know the ins and out details of it because I don't want to know'* (P1, 24).

**Question 9:  What do you do to make things better for yourself at school?**
[EA]
In responding to this question, the younger children focused, almost exclusively, on the things they do to stay as well as possible at school.  For example, Celine talked about having to be careful not to get wet: *'I was at a match and my friends were there and ... it was kinda late-ish and ... they all ... sat down on the cement.  I know that it was wet and damp and I know not to sit down and not to be in the rain and stuff'* (P3, 12).  Both children referred to the fact that they take medication while in school.  It would appear, however, that this is not entirely unproblematical.  Louis put it as follows: *'I try to take my medication'* (P4, 8).  The effort to which he refers would appear to be unavoidable if he is to feel well, as he continued: *'so I don't kind of feel rough or feel sick'* (P4, 8).  Celine had difficulty even articulating the fact that she takes her medication when others are in full view: *'Am, take my tablets as well ... make sure like, now I won't take up because ... people are around ... I still will'* (P3, 13).  The matter of academic progress featured but minimally in the responses of these early adolescents.  For Celine, the emphasis is on trying to understand and complete her homework: *'I kinda find the homework hard ... the learning ... I worry do I know it'* (P3, 14).  Louis simply tries to keep up with his class despite absences: *'I'd ask ... am ... for the work that we did and then I'd look at it and try to kind of catch up'* (P4, 8).

[LA]

The late adolescents also made it clear that they take steps to remain as well as possible at school though they portrayed such actions as not causing any particular problems.  Therese merely confirmed that she takes her medication with her: *'I bring my inhalers in with me and I bring my creon with me'* (P1, 25).  Pauline was equally reassuring in this regard, even pointing out that her friends also bring some medication to school on her behalf: *'they all have an inhaler of mine in their bags and everything and ... tablets ... they're just very good like that ... I'm lucky to have them like that'* (P2, 10).  Therese, on reflection, then added that her friend would take care of any unwelcome comments from classmates: *'I think if they did [make distasteful remarks]... I have a friend Genevieve and ... if anyone said oh what are you doing ... she'd just blurt what are you doing?  She's one of those type of girls, she just doesn't care ... she's very protective'* (P1, 25).  However, these participants appeared to link the enhancement of their lived experiences at school primarily with academic progress.  Accordingly, they presented as pro-active in their approach to the achievement of such progress.  In the case of Therese, this has entailed increasing the number of grinds she obtains each year: *'I have extra grinds ... this year.  I had them last year and in 3rd year as well but this year I have actually quite a lot of hours because of missing so much school'* (P1, 25).  While she manages, for the most part, to fit these classes into her school day, she cannot always do so and, therefore, sometimes has a rather lengthy day: *'I'm doing those within school hours and then on a Tuesday, after school, I have grinds as well.  So ... it's a long day in school because sometimes I go through my lunch hour'* (P1, 25).  The purpose of this arrangement seems to be to free her up for other activities after school: *'But I really ... don't mind because at least then I'm getting them done'* (P1, 26).  Pauline was not particularly forthcoming in this regard but appeared to suggest both that she knows what to do in the circumstances and that she takes a variety of actions*: 'Em ... I ... ask the girls what I missed ... I ... get notes off them and ... definitely even with that ... I find a way around it'* (P2, 13).  She concluded by saying *'it's not ... a ... big deal'* (P2, 13).


**Question 10:  How would you describe yourself as others see you at school?**

[EA]

This appeared to be quite a challenging question for these early adolescents. In attempting to respond to it, the overriding theme which emerged was that of uncertainty.  Such uncertainty seemed to arise both in relation to the identity of those with knowledge of their condition and in relation to the substance of such knowledge.  Louis put is as follows: *'Well, some people ... they*

*all know I have CF but they don't really know what CF is'* (P4, 9).  For him, this appears to suggest that he is not regarded as different and, also, to generate a certain relief: *'I suppose ... they just think I'm normal really.  Luckily ... I don't want to be treated differently.  I just want to be treated the same'* (P4, 9).  However, he was not really sure that he would be described as happy: *'Yeah ... well ...'* (P4, 9).  Celine admitted to uncertainty regarding the identity of those with knowledge of her condition at second level: *'Well I'm not too sure in secondary school'* (P3, 14).  She seemed to suggest that such knowledge existed at primary level and that it did not result in a particularly comforting view of her: *'I know in primary school ... my friends are always saying ... how can you be so nice'* (P3, 14).  Indeed, it became obvious, almost immediately, that this conversation caused her a degree of anxiety as she began to cry: *'Sorry [crying]'* (P3, 14).

[LA]

The responses of the older children to the above question, while somewhat tentative, nevertheless revealed a certain contentment regarding their situations.  This emerged despite that fact that they had dissimilar views on the specific subject of how others see them at school.  Therese, for example, considers that she is identified as different: *'I think some people kinda look at me and think that I'm different'* (P1, 26).  In her opinion, this perspective stems, primarily, from the differential treatment she receives in school: *'Because they see how the principal teacher treats me differently ... whenever the principal sees me in she's like oh it's great to see you in ... whereas she wouldn't say that to every other student'* (P1, 26).  However, she is also conscious of her CF as manifested in school: *'even going up and down the corridors ... if I started laughing or if I talk a lot I cough so if I ... go into a coughing fit ... people just look at me and they're like oh God, what's wrong with her'* (P1, 27).  In this context, she added the following observations: *'and then people who don't know me and don't know that I have CF probably think oh why is she like that'* (P1, 27).  At this point she admitted to not really knowing what others think: *'I wouldn't really know what way people see me'* (P1, 27).  Notwithstanding such uncertainty, she nevertheless concludes that she is probably regarded as different by many but as normal by numerous others, so, on the whole, everything is okay: *'But ... in general I think they look at me differently.  I know that ... a lot of people probably do ... but a lot of people see me as just a normal person so ... it's grand'* (P1, 27).  What she seems sure of, though, is that people consider her to be a happy and strong person.  Her evidence in this regard is as follows: *'A lot of people see me as a happy person ... a lot of people on facebook, that I'd be friends with, say ... to me that they really care about me and they love me and they love ... how much I'm happy*

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*[and] how strong I can be'* (P1, 27). She readily identifies with this description of herself: *'and I'm … a real happy person. I always smile and a lot of people just say to me like how do you do that like and I don't know'* (P1, 27). She continued: *'I don't know how to explain it … I'm a happy person because I have family and friends who're there for me all the time … and just getting through life … I'm a happy person 'cause I know that I'm going to do well and I've a good feeling myself as well, so …'* (P1, 27).

Pauline, on the other hand, does not consider that she is perceived as different: *'I don't think they see me as anything different'* (P2, 13). She attributes this perception to her own personal characteristics: *'I think they just see me as what I am. I'm just friendly and, you know, chatty and that.'* (P2, 13). She also appears to be putting it down to the fact that her CF is not really visible in school: *'half the girls wouldn't really even notice that I have CF or anything'* (P2, 13). However, she proceeds to qualify this immediately: *'only now I know all the girls in my year and … they only notice that I'd be taking tablets or when I'm off'* (P2, 14). Even in such situations, she contends that her classmates do not pose awkward questions; they merely want to be reassured that she is alright: *'if I'm sick or whatever, they'd be like are you okay?'* (P2, 14). In her opinion, everything is fine: *'it's no big deal'* (P2, 14). Moreover, she concludes by saying that her school friends are also of the same opinion: *'they all kinda know now but … it's not like a big deal or anything'* (P2, 14).

**Question 11: Why do you think others see you in this way at school?**

[EA]

The above question appeared to be as taxing as the previous one for the youngest children and to lead to avoidance of certain issues. In responding to the request for information regarding why others see her as they do at school, Celine made no reference to her academic performance. Instead, she focussed on the fact that people tend to say that she is nice and kind. In this regard, she stated that she did not know why this happens: *'I don't know. They always just say … that I'm the nicest and the kindest'* (P3, 15). However, she then added: *'I'm crying 'cause I'm happy [about this]'* (P3, 15). She went on to explain that she does not think these remarks are made because she has CF: *'Well, a lot of people wouldn't really know about it'* (P3, 16). At this point, she seemed to be suggesting that the number of people with knowledge of her condition even at primary level, where these comments were initially held to have been made, was small. Moreover, it is suggested that, in general, knowledge of CF in schools is limited: *'They don't*

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*really know about it. They just know it's CF, but they don't really know what it is or anything'* (P3, 16). She further confided that: *'only my good friends know. Like the only one that would really know would be my best friend'* (P3, 16). Louis, in respondong to this question, made no reference to his CF. Instead, he focused on the attribute which he considers most likely to represent the perception of him at school - his sporting ability – and on the reasons for this: *'I really am into my sport. Everything I talk about is sport'* (P4, 9). He also, however, appeared to suggest that his weaknesses in certain curricular areas, albeit due to absences, define him in the eyes of others at school: *'Yeah ... in the Irish I'm not very good 'cause I ... and some subjects I'm not very good ... 'cause I ... missed out ... a bit ...'* (P4, 10).

[LA]

The late adolescents appeared to suggest that that they are seen in particular ways at school largely because of their behaviour in that environment. Therese, for example, who considers that she is, in general, defined as different, returned to the issue of her coughing fits*: 'if I was in the ref having lunch ... me and the girls ... there would be like 10 of us sitting at the table ... and we'd just be talking and chatting and laughing and then I'd be the one doing lots of coughing out of everyone'* (P1, 28). She then referred to her practice of taking medication: *'and then if we were just walking around and I was taking my inhaler or taking my creon ... people would be looking and they'd be like oh ...'* (P1, 28). Pauline, who, on the contrary, does not think that she is perceived as different, also attributes this perception to her behaviour in school: *'It's just the way I am. Like I don't act as if there's something wrong ... as if I've a big problem. I just don't see the point in that. I'm just acting myself and act normal as if I don't have it. Like it doesn't affect me that way that I have to act, I feel like I have to act a certain way or act different because I have CF and they don't'* (P2, 15).

**Question 12: How do you feel about all of this?**

[EA]

Responses of the early adolescents to the above question suggested that they interpreted it as referring to their medical condition as school-going children and that discussion of their feelings regarding same is not particularly easy for them; indeed, circumventing and/or short-circuiting such discussion appeared to be their way of coping with such material. Celine, for example, though still a little weepy, initially replied: *'I'm happy enough ... I'm fine about it'* (P3, 17). However, she quickly moved on to repetition of her concerns around homework, adding, at this

juncture, that a friend also experiences stress in this regard: *'Oh, well I know that one of my friends gets kinda stressed about the homework too ... and ... she'd be worrying that she'd have it all done as well'* (P3, 18).  Louis put it as follows: *'Mm ... I kind of ... I don't really want to ... go off explaining it [CF] to them ... I ... say I have CF and it affects ... my tummy and so I have to take pills and things.  That's all ... I don't make too much of it'* (P4, 10).

[LA]

The older children also interpreted the above question as referring to their status as school-going children having CF but their responses appeared to suggest that discussion of their feelings in this regard is not particularly problematic because they have formed certain opinions.  Therese, for instance, although less expansive in respect of this question relative to others, was clear about her position*: 'Yeah.  It doesn't bother me ... People, they're going to judge you whether you do stuff or don't do stuff ... so what way they see me doesn't really bother me'* (P1, 28).  She added: *'I have my friends and family and they mean the world to me and ... once I have them I don't really care what other people think'* (P1, 28).  Besides, she holds the view that many who don't know her, don't judge her, though they might reveal a certain puzzlement in relation to her: *'But a lot of people ... that don't know me ... don't judge me ... they might say oh why do you do this and why is she like this but ...'* (P1, 28).  Pauline produced a remarkably similar response, albeit for a different reason: *'It doesn't bother me ... I don't want to act as if it's a big deal, it's a big problem like I have this.  I don't want a fuss ... about it'* (P2, 16).  She felt strongly, however, that greater communication between her medical team and her local school community would be unhelpful: *'I don't think they need to know ... it would make a difference'* (P2, 16).  When asked to elaborate on this, she rather animatedly continued as follows: *'I don't think they need to know though because I can deal with it ... I just miss as much time as I have to.  If I'm on antibiotics and I can't be in school that's when I'll miss it.  But if I'm not on antibiotics I can be in school ... I don't think it needs to be brought in ... a big deal like Pauline has CF ... she won't be in ... I just don't feel ... that needs to be done' (*P2, 17).  She concluded: *'I don't feel they need to know.  It's ... my meds ... but I can deal with it myself'* (P2, 17).

**Question 13:  Is going to school important to you?**

There was remarkable unanimity in the children's responses to this question, the dominant theme in each participant's account being the significance of school as the gateway to the achievement

of his/her goals.  In response to the specific question as posed above, all replied positively:
Therese – '*Yeah.  Definitely'* (P1, 29); Pauline – '*it is very important to me'* (P2, 18); Celine –
'*Yeah ... yeah'* (P3, 18); Louis - '*Yes, am ... yeah, definitely'* (P4, 10).  Their reasons for such
responses revealed a similar degree of concord.  For example, when asked why going to school is
important to them, they invariably referred to the potential it provides for realisation of their
ambitions.  For the younger children, such objectives were relatively modest: Celine – '*how to
read or add ... go to the shop ... [and] ... know the change like ... [to] ... get'* (P3, 18); Louis -
'*cause, well, making friends and also learning'* (P4, 10).  The older children had higher
aspirations: Therese - '*Cause I want to do well'* (P1, 29); Pauline – '*I want to do well ... I do like
and ... this year ... I want to keep well because I want to be able to do well'* (P2, 18).  The
motivation in the case of Therese was twofold.  Firstly, she wants to demonstrate to her parents
that she is capable of doing well: '*I want to prove to people that ... I can do it like.  Especially to
like my mam and my dad ... not that they don't think I can do it, they know I can but I just want to
show them that I really want to do well and that I can do well'* (P1, 29).  Secondly, she wants to
have prospects, a career and a family: '*in the end I want to have a future and I want to have a job
and I want to have a family'* (P1, 30).  Her overall aim is clear: '*When I'm older I want to do all
the normal things people do.  I don't want anything to change for me'* (P1, 30).  Pauline focused
more on academic success: '*Like it's my Leaving [Certificate] coming up so ... I just want to do
well so I can get a good Leaving'* (P2, 18).  However, she saw such success as heralding
additional achievements: '*and I can be able to go on and do whatever else I want to do'* (P2, 18).
Her ultimate goal is equally explicit: '*be happy with what I've done'* (P2, 18).

While unsolicited, each participant also raised the matter of nonattendance at school and of the
consequence of same.  In a word, they all suggested that such occurrences hamper the
achievement of goals.  Louis put it thus*: 'I know that if I don't go to school ... I won't achieve
very good things'* (P4, 11).  For Celine, it seemed to suggest attainment of a level of literacy
comparable with that of gypsies: '*if I didn't go to school I'd be kinda like tinkers ... some
travellers you know ... only know about pictures and stuff'* (P3, 18).  In the case of Pauline, while
missing school was represented as primarily affecting her contact with friends, she also appeared
to suggest that it would thwart her ambition, already stated, to do well: '*you know in first, second
and third year when I was missing and that ... it would annoy me not being there missing the
craic with the girls mostly but ... I want ... to be able to do well'* (P2, 18).  She then added: '*I
wouldn't like not want to be in school'* (P2, 18).  Therese was clear that missing school means

falling behind in school and that this bothers her: *'I don't like falling behind.  I didn't go in today or yesterday 'cause I wasn't well and it bothered me ... especially in 5ᵗʰ and 6ᵗʰ year like ... I don't want to be missing school'* (P1, 29).

### *4.4.4   Research Question 4: What does the future mean to you?*

Research Question 4 was designed to guide exploration of the fourth domain of enquiry: the impact of CF on the children's sense of the future.  This exploration required the construction of eight interview questions: Questions 14 – 21.  These questions covered topics such as: how they see themselves in the future; their reasons for thinking that they will succeed in achieving these future identities; their decision-making processes; their strategies for handling set-backs; their approach towards and concept of the future and of what is important about it for them.  Again, I will examine each of these questions separately and in sequence, below.

Questions 14 through to 21 each generated two themes: one representing that produced by the early adolescents and one representing that produced by the late adolescents.  I will deal, firstly, with the responses produced by the youngest participants (EA) and then proceed to those produced by the oldest participants (LA).

**Question 14:  How would you describe yourself as you would really like to be, as you see yourself in the future?**
[EA]
In responding to this question, the early adolescents revealed a tendency to focus on specific careers with which they appeared to be able to identify.  Celine chose the following options: *'I would like to be a hairdresser and a make-up artist'* (P3, 19).  She immediately added: *'But I'd also like to do something with horses and dogs'* (P3, 19).  Admitting to *'kind of'* having thought about her future, she explained that she had, in addition, considered being a beautician at one point, but had changed her mind about this.  She then returned to her initial choice: *'I really only want to do hair and make-up'* (P3, 20), commenting: *'I'd like to ... have my own salon'* (P3, 20). Louis opted for a career in the structural design area: *'kind of architect or something'* (P4, 11). While not really sure about this, he was, nevertheless, clear that he wanted a high-quality occupation: *'I don't know really ... I'd like to have a good job'* (P4, 11).  His next statement painted a very optimistic picture: *'Ah ... I'd like to see myself driving in a very smart car though'*

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(P4, 11).  Again, while uncertain about such a future scenario, he impressed as enjoying this particular discussion: *'Anyway, that might not happen'* (jolly here; P4, 11).


[LA]

The responses of the oldest children revealed a tendency to focus on a more generic concept of self with which they aimed to identify.  This includes such elements as obtaining the Leaving Certificate and gaining admission to college: Therese – *'well I'd like to finish school and get a good Leaving Cert'* (P1, 30); Pauline – *'I kinda just … haven't really thought past my Leaving Cert to be honest … I know I want to go to college'* (P2, 19).  Thereafter, it entails being in gainful employment: Pauline – *'I want to have a good job and I want to be able to do … well'* (P2, 18).  In addition, a priority for Therese is to travel: *'and travel.  I've told my mam I want to travel … travel around the world … just to see all the sights and places like'* (P1, 30).  Having achieved this goal, she then sees herself settling down and being happy: *'And then … when I come home from my travels … settle down and just be happy'* (P1, 30).  For Pauline, the priority is to be well: *'I just … I want to be healthy … and be well'* (P2, 19).


**Question 15:  How do you think you will succeed in becoming this person?**

[EA]

In responding to the question of how they think they will succeed in realising their future identities, as already outlined, the early adolescents focused on the educational process involved.  For Celine, the most immediate steps were clear*: 'I have to go to school anyway, and … I have to stay … to do Leaving Cert and do Junior Cert'* (P3, 21).  She seemed to suggest that she would need to reach a certain academic standard to do hairdressing: *'and to get the points to do … hairdressing'* (P3, 21).  Having qualified as a hairdresser, she planned to become a make-up artist.   In this regard, she stated that the route to such a qualification was varied: *'there's a few different ways'* (P3, 21).  However, she also stated that she favoured following the procedure adhered to by a cousin: *'my cousin … she's a teacher … and she has done a make-up course in college, so I was thinking if I went and did  … hairdressing I could do a make-up course in college and then I could qualify to be ... a make-up artist and a hairdresser'*  (P3, 21).  Louis concentrated on the quality of the second level educational establishment to which he would be transferring: *'I'm hoping I'm going to a really good secondary school.  Maybe [name of school] or something that has a good reputation'* (P4, 12).  He also appeared to suggest that studying subjects he likes would be important: *'And … do things I really like there'* (P4, 12).  Another

critical element for him was the support he would receive from staff: *'... and I kind of need teachers to help as well ... to ... tell me ... stuff'* (P4, 12).  Finally, he acknowledged that he, too, would have an input into the process: *'I think it's all up to me as well'* (P4, 12).

[LA]

When asked how they think they will succeed in realising their future identities, the late adolescents focused on the challenges they faced in this regard.  In both cases however, the challenges to which they referred related solely to the upcoming Leaving Certificate examination.  As Therese put it: *'I think just settle down now and just try and study and ... get a good Leaving Cert'* (P1, 31).  She then added: *'I know I'll have my admissions [going into hospital for IVs] ... I'm going to have so many admissions'* (P1, 31).  She clearly links her admissions with the stress she is enduring: *'It's related to stress and ... it's related to sleeping and not sleeping and just ... constantly on the go'* (P1, 32).  She elaborated on the subject of admissions as follows: *'I have to go in, every four to six weeks ... as they basically ... bring me up and they make me feel a lot better'* (P1, 32).  However, there is a downside which augments her stress: *'I'm so stressed out. Knowing that I'm missing school is making me ten times worse'* (P1, 31).  The problem is that this routine will continue: *'I have one [admission] over in this mid-term ... [but] ... I have admissions in and out like [all the time]'* (P1, 31).  She concluded that the entire situation is difficult: *'it's hard like.  When I come home from school at four o'clock I'm just wrecked tired and ... sometimes ... I don't even feel like eating because I'm so tired and I'm just ... not well which doesn't help'* (P1, 32).  Pauline was also concerned about the Leaving Certificate examination and about her ability to get through it: *'I'll just have to try my best so I can be able to do [it]'* (P2, 20).  She then focused on her academic weaknesses, pointing out that in the case of one of these she has already arranged extra tuition: *'I get grinds for Maths'* (P2, 21).  However, she still has to arrange additional help with another challenging area: *'I'm going to have to get help for Physics because that's one of the subjects I need'* (P2, 21).  The upshot of all of the above seems to be that she will have to cope with the remaining subjects herself: *'but I think the rest I'll just have to be able to do myself'* (P2, 21).

**Question 16: Why do you think you will become the person you see yourself becoming in the future?**

[EA]

The younger children revealed a lack of commitment in relation to their future identities when asked why they saw themselves in their chosen roles. Celine initially talked about always having liked her particular choices: *'Cause I've always loved doing hair and make-up on people'* (P3, 22). However, she suddenly seemed less certain about these choices: *'Yeah, but ... when I get older ... when I get to my Leaving Cert ... what I want to do will probably change'* (P3, 22). She then identified an additional role: *'now and again ... I think I could be a fitness instructor ...'* (giggles a little; P3, 23). This suggestion appeared to have been made because of its potential in relation to CF: *'it would be good too for the CF 'cause then I'd ... keep making sure I'd be keeping myself fit while training [others]'* (P3, 23). Louis did not mention his chosen future identity but seemed to suggest that he will realise his goal because he tends to take responsibility for such matters himself: *'I mean I try to do like as best as I can do'* (P4, 12).

[LA]

When asked why they thought they would realise their chosen future identities, the dominant theme in the responses of the late adolescents was that of a collective resolve in respect of this objective. In the case of Therese, her personal contribution appeared to be her strength and happiness: *'I don't want to sound cocky but ... I think I'm a strong person and I'm a happy person'* (P1, 32). However, she immediately proceeded to acknowledge her support structure: *'with people that care about me ... they're going to help me get through things and to succeed. With them like I know I'll become ... [that person]'* (P1, 33). A key member of this support structure is her mother: *'especially my mam ... my mam is like my sister like'* (P1, 33). She stated that her mother's particular form of support is as follows: *'to help me ... she's going to push me to my limits to get where I want to go. I know she will ... she already is'* (P1, 33). Her appreciation of such assistance is absolute: *'I need her to be like that. Other than that I'd just be, not feeling sorry for myself but just kinda ... not putting the effort in'* (P1, 33). Pauline was equally clear about the positive input of loved ones: *'Mam and Anthony ... are very good'* (P2, 22). She elaborated thus: *'they sat me down and they were like you are good at this ... you can ... go the easy route or you can go [do] something that you are good at that could be more benefit'* (P2, 22). For her part, she has been prepared to change subjects at school and, as a result, has to work harder in order to succeed in her new area of study: *'I had to change my subject. I was*

*doing Biology but now I'm doing Physics so now I have to push myself more to do that and to ...
do well in that subject'* (P2, 23).

**Question 17:  How did you decide to choose this role for yourself in the future?**

 [EA]

The youngest children revealed a distinct lack of exploration in their responses to the above
question.  While generally chatty, they had little to contribute in respect of this particular inquiry.
Celine returned to the issue of her on-going need for physiotherapy and seemed to suggest that in
choosing her future role, she would have to take same into account: *'I'm thinking ... when I get
older ... and ... doing work myself ... I will have to do my physio still'* (P3, 23).  Louis seemed to
link an interest in building and drawing to his choice of architecture: *'an architect ... I just love ...
building stuff.  I used to be really into leggo ... and I like ... drawing ... maps and ... pictures of
boats and cars and stuff.  Am ... inventing stuff ... and building camps and stuff'* (P4, 13).

[LA]

When asked how they decided to choose their future identities, the theme of exploration emerged
in the responses of the late adolescents.  In this regard, Therese talked about her work experience
as a student in Transition Year: *' I love working with kids but ... in fourth year I did work
experience and I went to ... my local primary school'* (P1, 34).  She recounted the events which
followed thus: *'and I worked with Junior Infants and I ended up doing ... not even five days, I
think I did four days and then that Friday I was really sick ... I picked up bugs off the little kids'*
(P1, 34).  The learning from that placement was significant: *'So ... that was when people were
saying look you can't do that, you need to work somewhere ... where you're not interacting with a
lot of people'* (P1, 35).  The outcome was disappointing: *' ... [it] really bothered me 'cause I love
... working with children, I love working with people'* (P1, 35).  She was then faced with having
to relinquish her chosen career and with the uncertainty which this entailed: *'So in general like
that was my goal to work as a primary school teacher but ... now ... I don't really know for sure
what I want to do yet'* (P1, 35).  Nevertheless, she has discovered another area of interest:
*'something to do with renewable energy is quite interesting as well'* (P1, 35).  In this regard, she
appears to have explored the third level requirements and to have established that at least one of
her chosen subjects will be useful: *'you'd need History or Geography and stuff like that for that
but I'm doing Business so that's one part of it done'* (P1, 35).  When considering her future
identity, Pauline initially took her academic record at school very much into account: *'I'm not*

*very academic ... I wouldn't be very good at school and ... I was gonna just be ... a beautician'* (P2, 21). However, she now considers that such a choice was *'just kind of an easy way out'* (P2, 21). The encouragement she received from a significant other was crucial: *'Anthony ... was talking to me about it and he said I'm really good at computers ... [that I've]... a good talent there'* (P2, 21). She was also keen on the area herself: *'it's something I like doing as well'* (P2, 21). Finally, some work experience in the field contributed further to her knowledge and decision-making in respect of her new career choice: *'obviously when I was doing work in summer I learned more about what I was doing ... so I ... just set my goals to something different then'* (P2, 21).

**Question 18: Do you have another plan if things do not work out at first?**

[EA]

The early adolescents revealed a degree of caution in their responses to the above question, albeit for different reasons. Celine, for example, while clearly lacking an alternative plan, was careful to present her situation in as positive a light as possible: *'Not at the moment. But ... I'm ... happy ... I'll think of something'* (P3, 24). She then seemed to imply that she actually has a number of options should things not work out at first: *'well there is the hairdressing or ... business or ... a physio or something'* (P3, 24). Moreover, her characterisation of the future, as represented in the following excerpt, suggests a wariness about having a definite strategy in relation to it: *'my friend for her birthday ... got a card and it said ... forget the past you can't change it, forget the future you can't predict it, forget about the present because I didn't get you one'* (P3, 24). Louis was also careful to point out that his lack of an alternative plan was not problematic: *'I'd really like to do being architect but if that doesn't work out that's fine. I'd be something else'* (P4, 14). His nervous laughter at this juncture, however, suggested that his next proposal was being put forward rather tentatively: *'Engineer. I went to ... Scotland ... and there was this kind of ... car ... it was like a remote control car but not really. It had lots of moving parts on it and stuff and ... I really enjoyed playing with that'* (P4, 14). The tentative nature of this proposal is continued in his final statement on the matter: *'Yeah ... I might be [an engineer] ... yeah'* (P4, 14).

[LA]

When asked whether they had another plan in the event that things did not work out as originally envisaged, the oldest children revealed a distinct absence of same in their responses. In the case of Therese, this appeared to be linked to some discouraging experiences in her life thus far. She

began as follows: *'What would a back-up plan be? I've thought of so many different things but I haven't really put down what exactly I would do. I didn't ... get what I wanted'* (P1, 36). She was very open about her vulnerability to set-backs and talked about a recent example as follows: *'when I got really sick ... last Christmas ... that took a lot out of me. I'd lost so much weight and I'd gotten so sick and I actually basically for a month was out of it, I was in ... intensive care ... which ... I'd never, ever been, even when I was a baby and diagnosed with CF ... and that scared me a lot'* (P1, 37). However, she concluded on a positive note: *'But ... I think ... I'd just keep trying. I wouldn't give up ... until I got where I wanted to go'* (P1, 37). Pauline would only say that she didn't have a back-up plan: *'No ... not really'* (P2, 23). She was reluctant to discuss how she might handle a set-back: *'I don't know'* (P2, 23), eventually adding: *'I haven't really thought about that'* (P2, 23).

**Question 19: Do you think about the future?**

[EA]

The early adolescents, when asked whether they think about the future, were somewhat ambivalent in terms of their responses. Celine, for example, alternated between *'Not really'* (P3, 25) and *'No'* (P3, 25), concluding with *'Nah ...'* (P3, 25). She explained thus: *'I kinda ... go with what goes on ... see what happens ... I just like ... get up tomorrow and see what's ... going on'* (P3, 25). Louis seemed, initially, to judge that he only thought about it infrequently: *'occasionally ... yeah ... occasionally'* (P4, 15). However, on reflection, he decided otherwise: *'I mean ... at school we ... talk quite a lot ... 'cause we're going to secondary school next year ... about the future, kind of, so ... yeah ... I do think about it'* (P4, 15). He settled on the following: *'Yeah ... definitely'* (P4, 15).

[LA]

The responses of the oldest children to the above question revealed a degree of strategic thinking on their part. Therese was clear that she differentiates between her future as a regular student and as somebody having CF. As regards the latter, she thinks about her future but doesn't like doing so: *'I think ... about my CF, how much it's going to deteriorate ... and if I'm going to get worse ... and how fast I'm going to ... go downhill ... sometimes I worry about that so ... I don't really like thinking about the future in that context'* (P1, 38). She added: *'I wouldn't ... [tend to] ... think of my CF because then I'd just bring myself down ... because a lot of people say ... the older you get the worse it gets'* (P1, 38). In contrast, however, she doesn't appear to have any

difficulty about contemplating her future as a regular student: *'I think about school'* (P1, 38). In the case of Pauline, the strategy is not to think about the future: *'it's not something that I think about'* (P2, 24). When questioned about her future in the context of school and whether she thinks about this, she admitted: *'Yeah ... that but that's as far as I've gone'* (P2, 24). She then explained: *'I want to be able to go to college and that'* (P2, 24), but repeated that she thinks about *'nothing really past that'* (P2, 24).

**Question 20:  What do you mean by the future?**

[EA]

In responding to the question of what they mean by the future, the theme which emerged among the youngest children was that of distance.   As Celine put it: *'When I'm kind of old and ... I ... have that job'* (P3, 26). She then added: *'I'd like to have a job that I'd like doing'* (P3, 26). She explained: *'Some people have their job but they just do it to get money and stuff ... what is it again ... I live to work or I work to live'* (P3, 26). Louis replied as follows: *'ten years time maybe'* (P4, 15). He went on to describe his concept of the future as *'something that I ... I don't want to think of ... like too often, be too worried about ... but I also kind of wanta think a bit about'* (P4, 16).

[LA]

The theme which emerged in the responses of the late adolescents to the above question was that of proximity.  However, these participants adopted very different approaches to this question. Therese was quite forthcoming in relation to what she means by the future.  She began thus: *'when I talk about the future, well it's what I want to do and what I'm gonna aim to do.  Whether I'll get there or not I don't know.  No-one ever knows if they're gonna ... It's the future that I want to have'* (P1, 39). She added: *'It's what I want to do when I'm older and when I'm an adult like ...'* (P1, 39). When asked about the time-frame she had in mind, she replied: *'I'd say about 5 years'* (P1, 40). This reality seemed to frighten her as she immediately stated: *'it's scary when you talk about it like that'* (P1, 40). She elaborated in this way: *'Ah, just to think how ... I'm not going to be in school anymore and I'm going to be in college in 5 years' time ... it's just crazy ... it's putting it into perspective like, that ... that's what's going to happen'* (P1, 40). Her plan regarding college would ideally involve leaving home, but she foresees some difficulties with this plan: *'I think if mam knew that she'd be trying to keep me at bay'* (P1, 41). There is also the matter of her own antipathy towards being away from home, even for an overnight in friends'

houses: *'But I'm a home bird. I actually ... don't know if I'll be able for that because ... even if a friend asked me to sleep over ... I'd never sleep over'* (P1, 42). This appears to puzzle her as it has not always been the case: *'I don't know why. I used to. I used to stay in everyone's house whenever but now I'm at the stage where come ... one or two o'clock in the morning I'd be like mam can you pick me up and she'd kill me but ... she knows me so well'* (P1, 42). Pauline was not very forthcoming in relation to what she means by the future. Her only comment was to suggest that it was near, that it means the next few years: *'Yeh'* (P2, 24).

**Question 21: What is important about the future for you?**

[EA]

When asked what was important about the future for them, the theme of happiness emerged in the responses of the early adolescents. Celine was clear: *'that I enjoy it anyway ... just ... enjoy it'* (P3, 27). However, she appeared to link the concept of pleasure with wellness as she immediately went on to the issue of health. In this regard, the imperative in her view is to continue with her physiotherapy: *'and that I don't just forget about the physio and stuff because I won't be well if I don't continue on with that'* (P3, 27). Louis simply said: *'being happy'* (P4, 16). In his case, though, the concept of pleasure appeared to be associated not only with *'being healthy'* (P4, 16) but also with *'earning a living kind of'* and being *'independent'* (P4, 16).

[LA]

The dominant theme in the responses of the older children to the above question was that of achievement. Therese put it thus: *'I think making the future ... like getting ... to the goals that I'm making, to be able to do them and succeed in them'* (P1, 43). The goals she singled out for mention were health-related: *'My health goals would be ... just to stay healthy'* (P1, 43); *'my CF goal would [be] ... to stay strong and take my meds'* (P1, 44). To stay strong would, however, appear to be quite a challenge and to continue to take her medication equally demanding given the rather tenuous link between both from her point of view. She explained by citing the experience of a friend: *'John ... we grew up together from day one when I was in hospital ... we'd been friends since day one. He was two years older than me. He passed away when he was thirteen. So I was eleven. I think when he passed away it kind of hit me and I was like he did all his meds, he was always in hospital ... he was always in and out'* (P1, 44). There were other examples: *'so many people that I've been friends with ... [took their medication but have passed away]'* (P1, 44). She mentioned a particular female friend: *'the same with Margaret and so many*

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*people said prayers for her and she always took her meds'* (P1, 44). She then recalled a conversation with her mother: *'I remember when Margaret passed away I said to mam ... what's the point in taking meds ... why take meds if it doesn't save you, if it doesn't help you ... I take my meds all the time and it's supposed to keep you well but it didn't for them which bothered me a lot'* (P1, 44). Her mother's advice was as follows: *'she said to me if you want to do well and you want to stay well you need to do it [to take your medication]'* (P1, 44). Hence her CF goal, as stated above: *'So that kinda ... made me realise I need to do it for myself and just stop and just get on with life'* (P1, 44). Pauline, while again not very talkative, nevertheless also revealed an achievement orientation: *'I want to be able to do well and have a good life'* (P2, 25). She paused, then restated her position regarding what was important about the future for her: *'just being able to ... have a good life'* (P2, 25).

### 4.4.5    Research Question 5: How is life for you?

Research Question 5 was designed to guide exploration of the fifth domain of enquiry: the impact of CF on the children's sense of life in general. This exploration required the construction of three interview questions: Questions 22 – 24. These questions covered topics such as: the positive aspects of their lives; the changes they would like to make to their lives and their main wish if such could be granted. As before, I will examine each of these questions separately and in sequence, below.

Questions 22 through to 24 each generated two themes: one representing that produced by the early adolescents and one representing that produced by the late adolescents. I will deal, firstly, with the responses produced by the youngest participants (EA) and then proceed to those produced by the oldest participants (LA).

**Question 22:  What is good about your life?**
[EA]
The theme of acknowledgement emerged in the responses of the younger participants to the question relating to what was good about their lives. Celine responded immediately thus: *'Well, I've good friends'* (P3, 28). She then added: *'My family'* (P3, 28). She confirmed: *'I ... enjoy life like'* (P3, 28). She was quite positive about her hospital and nurses: *'I like my hospital. They're good ... and ... my nurses are nice'* (P3, 30). However, she was not very positive about school*: 'I*

*don't love school ... people say they're the best days of your life but ... it's important 'cause you need to learn'* (P3, 29).  In the case of Louis, his initial thoughts centred on his address: *'living in such a nice place'* (P4, 17).  He then continued as follows: *'having lots of ... friends, lots of family, the care and ... having good education'* (P4, 17).

[LA]

Appreciation emerged as the main theme when the late adolescents were questioned regarding what was good about their lives.  Therese began by identifying those closest to her and their particular contribution*: 'what's good about my life is my friends and family ... that keep me going and ... make me feel like ... myself'* (P1, 49).  She then moved on to the other significant persons in her life: *'also the nurses in the hospital ... and the doctors ... are like a second family to us, especially to me ... they kinda ... keep me going'* (P1, 49).  She explained: *'I know all of them by name ... if one of them came in I'd be like hi, how are you ... I'd have a conversation with them'* (P1, 49).  She elaborated on the special input of the nurses: *'if I went into hospital and the nurses were ... kinda ... one word nurses ... that would bring you down completely whereas if you have people ... [you] can talk to and have a laugh with and ... they treat you like normal people ...'* (P1, 50).  Thus periods of confinement in hospital are tolerable: *'you wouldn't even think you were in hospital the way they go on with you  ... if it comes to me staying in hospital ... I could stay there for two weeks on end ... I'm sixteen now ...[and] mam ... has Frank and Edel to deal with at home, so she can't stay with me but ... I'd be fine staying up there'* (P1, 50).  Finally, she included school: *'school is good ... I'm happy in school'* (P1, 51).  She continued*: 'sometimes I get a bit ... down because I'm behind in certain things ... but in general ... I like school now and I have to say if I didn't go to school I'd probably be depressed because I wouldn't have anything to do or to work towards'* (P1, 51).  Pauline initially focused on her immediate family: *'I've a really good family.  Like my mam and Anthony ... and Joseph ... my brother.  He's younger.  He's eleven.  They're always there'* (P2, 27).  She went on to include her extended family: *'And then my nanny and grandad ... they're brilliant ... they're always there as well'* (P2, 27).  She concluded by incorporating her friends: *'My friends as well ... I just, I love them ... they're so good and we're all so close.* (P2, 27).

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**Question 23: What would you like to change about your life?**

[EA]

A lack of enthusiasm emerged in the responses of the early adolescents to the question of what they would like to change about their lives. Celine put it like this: *'there's nothing really I would like to change about my life ... there isn't actually like'* (P3, 29). She continued: *'Seriously ... people are saying that there's a drug out for one gene of Cystic Fibrosis but ... it doesn't really make a difference ... you know'* (P3, 30). She added: *'I don't really ... think about having it. I just, you know, get on with it'* (P3, 30). Louis was equally unenthusiastic but made no reference to CF: *'Ah, I don't know ... we could live on the other side of town'* (P4, 18). He elaborated: *'I prefer the other side of town over there. It's kinda nice'* (P4, 18). However, he then concluded: *'but this is fine ... I really don't know'* (P4, 18).


[LA]

As regards the older children, the issue of CF was very much to the fore when asked what they would like to change about their lives. These participants held different views in respect of this however. For example, Therese considers that having CF has generated certain positive outcomes in her case: *'I think it's made me a stronger person and made me more willing to do things'* (P1, 52). She continued: *'in a way ... I wouldn't like to have it but ... it's a part of life and I've grown up with it ... and ... I'm a happy person ... it's not like it's made me unhappy 'cause ... I'm living with it everyday and it hasn't changed my life in any way'* (P1, 52). She qualified her last remark immediately: *'It has ... in the context of being sick and in and out of hospital ... none of my friends have to do that and I have to do meds and stuff like that'* (P1, 52). In sum, her position is as follows: *'I wouldn't change it [her life] ... A lot of people would probably say ... having CF ... but ... I don't think I'd change anything'* (P1, 52). In the latter context, she elaborated in relation to certain other aspects of her life: *'I have friends and family that mean the world to me and I wouldn't change any of them'* (P1, 52). She also talked about her medical care and team: *'the hospital ... has actually been amazing. I couldn't have asked for a better hospital and the nurses and doctors and everyone's just great ... you can't complain about them ... I wouldn't change them'* (P1, 53). Her position regarding school was less definitive: *'school ... ... the way school is now I'm happy. Like I'm not unhappy in school'* (P1, 52). For Pauline, there was no ambiguity when asked what she would like to change about her life: *'I wish I didn't have CF ... it really is a pain to have but ... you have to just deal with it'* (P2, 29).

**Question 24:  If you had one wish, what would that be?**

[EA]

In responding to the question regarding what they would wish for if they could make one wish the younger participants revealed an acceptance of their current situation.  Celine initially joked: *'well, first of all 'twd be to have more wishes'* (P3, 31), but then stated: *'just be happy and enjoy life probably ... like just to keep enjoying it'* (P3, 31).  She added: *'Yeah ... 'cause what good's money and everything'* (P3, 31).  Louis put it as follows: *'Well, I think it's ... okay having it [CF]'* (P4, 19).  He explained: *'I mean it's kind of annoying sometimes, like ... going over to a friend's house for a sleep-over, or something and having to do ... my inhaler thing ... but otherwise ... everything's kind of fine'* (P4, 19).  He concluded: *'I don't think it affects me kind of ... it doesn't really affect me [much]'* (P4, 20).

[LA]

The dominant theme in the responses of the late adolescents to the above question was that of being free of CF. Therese was unequivocal in terms of her reply: *'My wish ... that there would be no illnesses ... at all ... not just CF like, in general ... just none ... at all'* (P1, 53).  Pauline was equally definitive: *'I didn't have CF'* (P2, 29).  She continued: *'I wouldn't be sick and ... I don't know what else.  I think it would change a lot of things'* (P2, 29).  She elaborated: *'I'd feel better. I wouldn't have to take tablets.  I wouldn't always ... have to take medicine.  I wouldn't always have to watch my weight ... you know, different things that ... [not having] it would make me feel better and easier about'* (P2, 30).

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# Chapter 5. Findings - Discussion

## 5.1   Introduction

In this chapter I analyze my findings, discussing them in relation to my research questions and domains of enquiry.  I then reflect on my findings with reference to the research literature and to issues raised in Chapter 2 (Literature Review, pp. 13 - 39) of this study.

The aim of my research was to explore the identity construction of four school-going children having a diagnosis of CF with a view to establishing whether or not they consider themselves to be disabled and to have a disability.  The question motivating this study, therefore, is: What kind of identity are children with CF constructing as they make their way through school?

## 5.2   Discussion of Findings with reference to Research Questions and Domains

### 5.2.1   Research Question 1: What is CF and how does it affect you?
### Domain 1: What CF means to the Children

**A burden/a nuisance**

The early adolescents appeared to liken CF to a burden, in that it demands certain actions on their part if they wish to be well.  These were identified as taking medication, exercising and watching their diets.  In addition, there is the obligation to do one's physiotherapy, a theme to which Celine frequently returns.  However, such undertakings were represented, in the main, as having but nuisance value, the associated difficulties, though experienced on a daily basis, being primarily physical in nature and, in essence, more bothersome than severe.

**Being scared/a routine**

For the older children, on the other hand, CF seems to represent something much more sinister in nature.  Claiming not to really know what it is, they contended that they did not want to know. When developing this theme, however, it became apparent that they had acquired certain knowledge in respect of it.  This seems to have come about as a result of some preliminary research, at earlier points in their lives, which appeared not only to scare them but also to

discourage them from pursuit of further information.  Moreover, both participants have developed similar strategies in relation the general issue of CF: to deal with difficulties as they occur. With regard to their onerous daily regimens, a four-hour exercise for Therese, they revealed that same had become routine.  This practice is frequently reported in the literature in terms of a normalization process, the purpose of which is to enable the extraordinary to become commonplace, thus allowing the individual to avoid being the subject of undue attention (Wise, 2002).  Nevertheless, that CF represents both a physical and an emotional challenge for these participants is clear. For Pauline, it denotes something quite negative – *'a horrible illness'* (P2, 6); for Therese, who appears more accepting, *'it's just a part of life'* (P1, 12).

That they have attempted to face up to this challenge in ways which meet their needs is encouraging.

### *5.2.2   Research Question 2: Who are you and why do you say you are who you say you are?*  **Domain 2: The Impact of CF on the Children's Sense of Self**

**Being sporty and physically active**

On being asked to tell me a little about themselves, I was immediately struck by the emphasis placed, on the part of each participant, on being sporty and physically active.  The variety of activities engaged in by them was remarkable: rugby, hurling, camogie, sailing, swimming, taiquando, exercising and dancing.  Not only did they appear to enjoy these activities but, in Pauline's case, a relatively high standard had been achieved.  Louis impressed as anxious to identify with tough, masculine team sports. This finding is not usually reported in the literature on the chronically ill (Griffiths, Schweitzer and Yates, 2011) but such activity is particularly beneficial for children with CF and may be engaged in for this reason.

**Being different**

When invited to describe themselves as they really are, as they see themselves, their unanimity vis-à-vis being different was quite striking.  While approaching this question in individual fashion, the readiness with which they broached the theme of difference was perhaps inescapable, the constant negotiation of normal and different being a recurring theme in the literature on CF (Jessup and Parkinson, 2010).   Therese, for example, began by describing herself as a happy person but proceeded, directly, to explain that she has to deal with a lot of 'stuff' and that her

approach in such situations is to 'act' like a normal person. In this context, it would appear that she is of the view that she is not normal but that she knows how normal people 'act' and that she can emulate their actions. Moreover, she proclaimed that when talking to others with CF, such conversations are *'more or less ... the same'* (P1, 6) as those conducted by normal people. This suggests that others with CF are, like herself, not normal and that conversations between people with CF are different to those of normal people. It is difficult not to conclude that such conversations are borne of experiences which are also different, that non-normal things happen to people with CF. Thus it would seem that, in her view, at least two categories of people exist: those having CF and those not having it. While the latter are clearly identified by Therese as normal, the implication is that the former are not normal, that they are indeed different.

Though Therese made no reference, at any point, to wanting to be normal, despite a tendency to 'act' like normal people, the younger children impressed as generally less self-assured. Celine, for example, having struggled to produce a description of herself, confining same to a remark about liking company, eventually managed to get the following on record: *'I just like kinda just like just be normal kinda'* (P3, 12). This not only confirms a belief that she is different but also a desire to be normal. Having to do physiotherapy every day to get the mucous from her lungs would appear to be contributing to her perception of herself as different. For Louis, it is not so straightforward. Describing himself as a perfectionist, he admitted to knowing that he has CF but to having a preference for seeing himself *'just as someone kind of normal'* (P4, 2). In other words, he believes himself to be 'kind of' different. Accordingly, he tries *'to be as kind of as normal as possible'* (P4, 2). This appears to suggest not only a desire to be as normal as possible but also a conscious effort to 'be' as normal as possible. He seems to believe that compliance with his medical regimen will enable him to be that normal person.

Pauline was less certain about the true meaning of 'normal'. In responding to this question, she pointed out that she has had CF from birth and that she has never known what it is not to have it (cf Jessop and Parkinson, 2010). In this context, she then quickly added, albeit tentatively, that she does not consider her situation to be *'weird or different'* (P2, 8). The fact that she voluntarily introduced such terminology into her description of herself, however, suggests at least a modicum of doubt regarding her status. Furthermore, that she should include references to her medical regimen at this juncture suggests that it contributes to those doubts. In sum, it would appear that

the reality of her situation, though 'normal' for her, suggests at least the probability of being different.

**Being supported**

When questioned as to how they managed to become their current selves, the participants appeared to link the 'how' aspect with a focus on particular facets of their identities. In every case, the 'how' was reported to have been achieved due to the support of family members, particularly mothers; Therese and Louis also mentioned their friends. The defining characteristics chosen by participants to illustrate this support differed, however. In the case of Therese, for example, it is her 'survivor' identity, which she chose to highlight at this juncture. Thus, CF contributes hugely to her sense of self. Pauline chose to talk about her identity as a champion swimmer, making no reference to CF. The younger children also omitted any reference to CF: Celine focused on extra-curricular activities while Louis referred to his *'nice home'* (P4, 3), suggesting that he attributes his current identity both to the support of family members and to the possession of certain material assets.

**Having experiences and interests**

The query concerning their reasons for considering themselves to be as they say they really are, revealed a general consensus on the part of participants that their experiences and interests contribute to same. However, once again, the consensus did not extend to the specifics regarding these experiences and interests and their approach to the defining characteristic which they all share, their chronic illness, ranged from avoidance of any reference to it as a contributory factor to complete acceptance of it as having a role in relation to their current identity. Louis, for example, talked about having lived abroad in addition to his interest in having *'things done properly'* (P4, 3). Given that he believes himself to be 'kind of' different, it is perhaps not unreasonable to infer that he may do so for reasons other than the fact that he has CF.

Celine, while avoiding specific mention of CF, nevertheles, concentrated on an aspect of her lived experience which is directly related to it: her physiotherapy regime. Clearly this plays a huge part in her life and is an imperative if she is to stay well. That its significance for people with CF is not generally recognised, even in the media, seems to irritate her. An additional remark appears to suggest a current self which is 'nice' but the motivation in this regard implies expediency, i.e., it is a strategic as distinct from an authentic feature of her identity.

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Pauline initiated her response by focusing on her interests as key factors which contribute to her current identity. However, she progressed to the issue of CF, stating that in describing herself she refrains from any mention of it. This suggests that while aware of the role of CF in her life she chooses not to draw attention to it. Thus, it would appear that she also chooses to believe that it does not have a function in relation to her current identity.

This approach stands in sharp contrast to that of Therese, who appears to directly link her medical condition with her current identity: *'CF is kind of a part of me and it's made me who I am. Like if I didn't have my CF ... I'd say I'd probably be a different person'* (P1, 11). Furthermore, she appears to embrace this identity as she considers that her CF – related experiences, though challenging, have enabled her to develop personal strength, additional drive and the motivation to achieve a level of autonomy and of success comparable to those not having CF. Ultimately, she wants to prove to others that CF is not going to hold her back in any way.

### 5.2.3   Research Question 3: How does CF affect your school life and others' perceptions of you?
### Domain 3: The Impact of CF on the Children's School Life

**Little disruption**

The early adolescents revealed a reluctance to respond, either positively or negatively, to the query regarding whether or not having CF makes a difference at school. Nevertheless, that their experiences at primary level suggest little disruption or interference appears evident. For Celine, the cricial issue seems to be whether or not she has to explain her actions to others, for example, the taking of medication at lunch-times. This suggests that she's happiest when people do not raise the subject of CF. She appears to be saying that this was a feature of her time in primary school. However, this is not to suggest that people at primary level were unaware of her condition. Indeed, she states that at primary level *'people just know you have CF'* (P3, 7); it's just that they wouldn't ask any questions about it. Thus, she appears to be saying both that such people had been told something about her illness and that they had simply accepted what they had been told. These circumstances permitted her to avoid any mention of CF in primary school, to 'presume' that people have sufficient information in respect of it and to be at ease in that

environment. Perhaps this explains why Louis, who was still in the primary system, also appeared not to be experiencing any real difficulties at school. In this regard, he seemed to merely experience a little disruption in the context of enforced absences which entailed being unable to complete homework assignments.

However, having just transitioned into the second level sytem and begun attending a new school, Celine was clearly undergoing some unanticipated experiences at the time of our meeting, a not uncommon occurrence at such critical periods in children's schooling (Williams, Gannon and Soon, 2011). Again, while not classifiable as significant, the interference to which she was being exposed seemed to occur primarily at lunch-times when taking her medication. This action now appeared to require some comment. It was also possible that her second-level classmates, irrespective of their degree of knowledge of CF, did not wish to completely ignore her personal situation. In sum, this study would appear to suggest that transitioning into secondary school has the potential to lead to challenges for children with CF which they may not have experienced at primary level.

**Considerable disruption**

That the older children appeared to confirm the reality of a more taxing environment at second level is indisputable because, from the outset, they were clear that having CF makes a difference at school, that it leads to considerable disruption or interference (Jessup and Parkinson, 2010). In this regard, Therese revealed that CF - related tiredness makes it difficult to withstand the variety of demands that the senior cycle, in particular, places on students. This would appear to suggest that when one's health is progressively deteriorating, to simultaneously have to engage in ever more advanced studies, may be rather problematical. When one adds intermittent and sometimes prolonged absenteeism into the mix, the scale of the difficulties becomes more apparent. In this regard, both participants stated that trying to catch up with everybody else and not fall behind was 'hard' and 'annoying'. However, it seems clear that they want to stay up with everybody else and to succeed in school.

In addition, it would appear that trying to maintain regular relationships with classmates can also be challenging for late adolescents with CF. In this context, while both participants raised the matter, their talk revealed somewhat dissimilar experiences and relationships. Pauline, for example, who specifically mentioned *'not being able to do things with … friends'* (P2, 9; cf also

Griffiths, Schweitzer and Yates, 2011) as a key consequence of having CF, nevertheless enjoys continuous physical contact with and emotional support from them during periods of serious illness. This is made possible because, on such occasions, her classmates visit her after school hours, stay with her and support her.

For Therese, on the other hand, having CF appears to result in curtailment, not just of her activities with classmates but also of physical contact with and emotional support from them, especially during periods of serious ill health. This seems to occur, primarily, because of her personal approach to her illness. The latter includes a deliberate policy of not talking to friends about it, even when compelled to miss school because of it. In such instances, unlike Pauline, she keeps in touch with her friends via facebook and texts. However, though she believes that people know why she is out of school, she still maintains her policy of not discussing her illness during such interactions. For their part, it would appear that her classmates comply with her tacit aspiration. She also appears to need a similar level of compliance on the part of a close friend in order to prevent being reminded, at school, about a girl with CF who has *'passed away'* (P1, 18) and whose passing she has found *'really hard'* (P1, 18). In these circumstances, it is perhaps not surprising that her teachers also appear to observe a certain silence in relation to CF. That this practice may not always be helpful but may, despite everybody's best efforts, lead to a degree of discomfort generally, does not appear to be fully appreciated by Therese: when a room change was quietly arranged to facilitate her, for instance, she didn't seem to anticipate others' reactions or to comprehend the need, at times, for teachers to have the freedom to explain management decisions and for pupils to have the opportunity to receive such explanations.

**Reduction of embarrassment**

When invited to suggest what might make things better for them at school, the younger children, somewhat modestly, converged on the theme of embarrassment reduction. Interestingly, however, the proposal put forward by Louis about not having to study Irish had nothing to do with CF. For him, the critical issue at this point in his schooling appeared not to be his illness; rather it appeared to be his perceived lack of competency with regard to the Irish language which, in all probability, he didn't have to study until he returned to Ireland and became part of the Irish education system. His discomfiture in articulating this limitation, which doubtless was obvious in class, was palpable. Furthermore, given his belief in his perfectionism, that he should revisit this issue on a couple of occasions throughout our meeting was perhaps not surprising.

Celine, on the other hand, while not mentioning CF directly, appeared to be referring to a situation which is connected to her condition but which is, also, a source of embarrassment to her: being the only pupil allowed to take off a jumper in class if feeling a need to do so. She is clearly uneasy about the effect this is having on other children. Such unease is compounded by the fact that at least one of her classmates is determined to push the issue: he *'keeps asking'* (P3, 10) to be given similar permission. That he is constantly refused by their teachers, without explanation, does not help. Nevertheless, that her classmates do not raise the matter with her appears to provide a measure of relief and the space to avoid discussion of her situation, an imperative for Celine which has already been noted above.

**Having everything under control**

The responses of the late adolescents with regard to what might make things better for them at school appeared to imply that, in the circumstances, everything was under control. Indeed, unlike the younger children and despite their relatively more serious health problems, they didn't provide any suggestions in this regard. Instead, while Pauline was clear that not having CF would obviously make a difference, both participants seemed to be claiming that their needs were being met in their respective schools: access to staff, facilities, grinds, subject notes and additional help during periods of hospitalization. With regard to the latter, Therese also willingly pointed out that while communication between the teachers in her hospital school and in her own local school had been negligible *'up until this year'* (P1, 21), both sets of teachers had agreed to remain in contact throughout *'5th and 6th year'* (P1, 21), i.e., until her Leaving Certificate at the end of her secondary schooling. However, she did not favour any changes in respect of these routines, fearing that same might lead to differential treatment of her in her local school. Moreover, she expressed satisfaction with the current level of knowledge of her classmates regarding CF, which she perceives to be insignificant, for the same reason. In other words, the normalisation and information management practices so frequently reported on in the literature in this area (cf. Chapter 2, pp. 26 - 27) are being employed here also as part of the adjustment process applying in the case of CF.

**Compliance with CF regimen**

The query regarding the steps they take to make things better for themselves at school appeared to have been interpreted by the younger children as referring, primarily, to medical matters. For

example, Celine talked about having to be careful not to sit on damp or wet surfaces during school games. Both participants referred to the fact that they take medication while in school. Effecting this particular measure, however, seemed somewhat problematical, a feature of CF which is regularly reported on in the literature (Jessup and Parkinson, 2010). As Louis put it: *'I try to take my medication'* (P4, 8). Celine had difficulty even articulating the fact that she takes medication when others are in full view: *'Am, take my tablets as well ... make sure like, now I won't take up because ... people are around ... I still will'* (P3, 13). In sum, it would appear that, while essential, compliance with their medical regimens requires a degree of discipline and of self-confidence when in the company of others not having such constraints.

The matter of academic progress featured but minimally in the responses of these early adolescents. For Celine, the emphasis is on trying to understand and complete her homework; Louis simply tries to keep up with his class between absences.

**Managing with the help of friends**

On being questioned about the steps they take to make things better for themselves at school, the late adolescents also made it clear that they try to remain as well as possible at school but they portrayed the requisite measures in respect of same as not causing any particular problems. They simply bring their medications with them and take them, as necessary. In this context, Pauline revealed that her friends also *'all have an inhaler of [hers] in their bags and everything and ... tablets'* (P2, 10), thus ensuring that she can adhere to her medical regime. This very practical and supportive gesture makes her feel 'lucky' to have such 'good' friends and, no doubt, contributes to an enhanced experience for her in that environment. In similar vein, Therese reported having a particularly 'protective' friend on whom she can rely to take care of any unwelcome comments from classmates. In other words, she too avails of the assistance of trusted others in an effort to make things better for herself at school.

However, unlike the early adolescents, these participants appeared to link the enhancement of their lived experiences at school primarily with academic progress. Again, they portrayed the steps they take in relation to this matter as not particularly exceptional: they basically seek out as much extra tuition and help as they deem necessary. In this regard, Therese enjoys much support from a variety of sources, as she is enabled to access many hours of additional instruction, both during and after school, on a regular basis. Pauline appeared to suggest not only that she takes a

variety of actions, as required, but also that she always manages to 'find a way around' her particular predicament. Nevertheless, that the latter can involve asking *'the girls what [she] missed'* (P2, 13) and being supported by good friends is readily acknowledged by her. Thus, once again, these participants presented as pro-active in the mobilization of others when their assistance is required

**Uncertainty**

When invited to describe themselves as others see them at school, the overriding theme to emerge in the responses of the early adolescents was that of uncertainty. This uncertainty seemed to arise both in relation to the identity of those with knowledge of their condition and in relation to the substance of that knowledge. It appears that these young participants interpreted the above task as relating directly to their health status, to their identity as school-going children having CF. In this circumstance, since the matter is not discussed, that there should be uncertainty on their part is understandable. Even Louis, who declared that *'they all know'* (P4, 9) he has CF only did so after some hesitation. It is as if he would like to think that only *'some people'* (P4, 9) know but that commonsense dictates otherwise. Interestingly, he also states that his classmates *'don't really know what CF is'* (P4, 9). Again, given the absence of any evidence to support this statement he cannot, in truth, be sure that it is correct but commonsense would dictate that it is. Moreover, assuming that it is indeed correct, any associated uncertainty would appear to be overshadowed by the possibilities that such a statement allows, e.g., that others may 'see' him as just another student. In this regard, his use of the term 'luckily' suggests that it would be unfortunate if they thought otherwise. Celine, however, while appearing to confirm the assertion on the part of Louis that 'they all know' at primary level, seemed at the same time to refute any suggestion that such knowledge may have accorded her an unexceptional profile. In reality, it unfortunately did not appear to result in a particularly comforting view of her. Questions such as *'how can you be so nice?'* (P3, 14) which reportedly were posed on a regular basis by her friends, seemed to genuinely unnerve her, a fact which became obvious during our meeting as she began to cry when recounting same. She was clear, though, that the identity of those with knowledge of her condition at second level remained uncertain. This, no doubt, was due in some measure to having but recently transitioned into her new school. Given this situation, that she should also harbour a degree of uncertainty in relation to the substance of that knowledge could be expected and may have contributed to her general anxiety in relation to this query.

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**Contentment**

The older children revealed a certain contentment in their responses when invited to disclose how they would describe themselves as others see them at school. This was evident despite that fact that they had dissimilar views on the specific subject of how others see them at school.

Therese, for example, essentially considers that it is her identity as a school-going person having CF which resonates with her classmates. She appears to attribute this perception, primarily, to the differential treatment she receives in school, especially at the hands of the principal teacher. However, that she is also conscious of her CF as manifested in school seems clear. Such matters, no doubt, make it difficult to simply blend in; indeed they militate against the building of an inconspicuous profile in that environment. A complicating element is her assertion that some pupils *'don't know [her] and don't know that [she has] CF'* (P1, 27). When one includes the fact that she never discusses her illness at school, it is easy to understand why she appeared to conclude that she *'wouldn't really know what way people see [her]'* (P1, 27), that people will probably have different opinions about her and that on the whole everything is 'grand'. What seems to contribute to her contentment in this regard, though, is the fact that *'a lot of people'* (P1, 27) consider her to be a happy and a strong person, a description of herself with which she readily identifies.

Pauline, on the other hand, appears to consider that she is perceived to have a regular profile at school. She seems to attribute this perception, primarily, to her own personal characteristics and behaviour, e.g., being *'friendly and ... chatty'* (P2, 13). However, the fact that her illness is not really visible in school also contributes to this particular assessment and to her belief that *'half the girls wouldn't really even notice that [she has] CF or anything'* (P2, 13), while those in her year *'only notice that ... [she takes] ... tablets or when [she's] off'* (P2, 14). Besides, when unwell, she holds that her classmates merely wish to be reassured that she is 'okay'. Given that many of these same friends are reported to voluntarily carry medication in their bags to ensure an unbroken supply for her while in school and to virtually maintain a vigil by her side when seriously ill, it is difficult not to conclude but that Pauline very deliberately separates her identity as a school-goer from her identity as a person having CF and a chronic illness. The former permits her to function as a regular student when in school. That she appears at ease with this situation seems clear: she not only pointed out that, in her opinion, having CF is *'no big deal'*

(P2, 14) at school (confirming research by Charmaz, 1983) but she also stated that her friends are of the same opinion in this regard. Hence, in sum, everything is fine.

**Strengths & weaknesses at school**

When invited to provide their reasons for thinking that others see them as they believe they do in school, the responses of the youngest children revealed a tendency to focus on some of their respective strengths and weaknesses. This focus led to strategic avoidance of certain other matters. Celine, for example, made no reference to her academic performance at school. Instead, she concentrated on the fact that people tend to describe her as *'the nicest and the kindest'* (P3, 15). While appearing to regard such qualities as assets, she shed a few tears when uttering this phrase and impressed as having some misgivings in relation to it. Nevertheless, she claimed not to know why her classmates describe her in these terms and to be crying *'cause I'm happy [about this]'* (P3, 15). However, she then proceeded to declare her belief that the remarks had nothing to do with her illness. Her reasoning was interesting: *'Well, a lot of people wouldn't really know about it'* (P3, 16). In this regard, she appeared to contradict the impression she had conveyed earlier that they all know at primary level, the context in which these observations were initially held to have been made. In reality, given that her illness is not discussed at school, it seems conceivable that while Celine doesn't actually know why these remarks are being made about her and could not know whether there is a link with CF, she nevertheless suspects a link with CF. In this circumstance, it also appears conceivable that she would not only like to think that the number of people with knowledge of her condition remains small but also that these people wouldn't *'really know about it ... what it is or anything'* (P3, 16). Similar perceptions are evidenced in the literature on chronic illness and linked with a lack of understanding in lay environments of such matters (Williams, Gannon and Soon, 2011).

Louis, in respondong to this question, made no reference to CF thus reinforcing the notion that he entertains the possibility that others may 'see' him as just another student. Accordingly, he focused on the attribute which he clearly considers most likely to represent the perception of him at school: his sporting ability. His reasons were credible: *'I really am into my sport. Everything I talk about is sport'* (P4, 9). However, he also appeared to suggest that his weaknesses in certain curricular areas, albeit due to absences, may further define him in the eyes of others at school. In this context, while reiterating his concerns regarding his standard of Irish, he seemed to suggest

additional problems in relation to 'some' other subjects in which he is *'not very good 'cause ... [he] ... missed out ... a bit'* (P4, 10).

**Behaviour in school**

The late adolescents appeared to suggest that others see them as they do in school largely because of their own behaviour in that environment. It was interesting that both participants should communicate similar reactions to this query despite holding dissimilar views on the subject of how others see them at school. Therese, for example, considers that she is, in general, defined as having an atypical profile and that this perception is linked to behaviour which is consistent with having CF. In this regard, she returned to the specific issue of the coughing fits which evidently occur during free periods, disrupting her leisure time with friends, but over which she would seem to have little control. She also has to take medication at lunch times or perhaps when *'just walking around'* (P1, 28). In sum, it would appear that it is the inability to intermingle, in inconspicuous fashion, with friends, particularly outside class periods, due to CF, which seems to matter most in her opinion. Accordingly, how she is treated by the school community, what people think of her, whether or not they know about her illness and/or their level of knowledge regarding CF appear, on the whole, to be relatively inconsequential.

Pauline, on the other hand, appears to consider that she is perceived as having a regular profile at school. Again, she seems to suggest that this is linked to behaviour, on her part, which is consistent with not having CF. In elucidating the latter, she made the following remarks: *'Like I don't act as if there's something wrong ... as if I've a big problem'* (P2, 15). In other words, she behaves as if there is nothing wrong with her, as if she does not have problems. Given, as already stated above, that her illness is not really visible at school in any event, it is perhaps not surprising that she doesn't see the point in doing otherwise.

**Discussion as problematic**

On being asked how they feel about all of this, the early adolescents, having interpreted the query as referring to their medical condition, revealed that discussion of the matter is problematic. Indeed, that circumventing and/or short-circuiting such discussion appeared to be their way of coping with this issue became rather obvious. Accordingly, Celine, while initially proclaiming, albeit tearfully, to be *'happy enough ... fine about it'* (P3, 17), quickly moved on to repetition of her concerns around homework, adding, at this juncture, that a friend also experiences stress in

this regard. Louis, while ostensibly indicating that he employs the aforementioned strategy in relation to his classmates, was in effect also applying it to me. Nevertheless, he revealed the following: that he doesn't *'really want to ... go off explaining it'* (P4, 10) to anybody; that he simply says that he has CF, that it affects his tummy and that he therefore has to take certain medication. He then concluded: *'That's all ... I don't make too much of it'* (P4, 10). In sum, it would appear that 'all of this' is rather difficult and not something which these children wish to explore in any detail.

**Having opinions**

Having also interpreted the above query regarding their feelings 'about all of this' as referring to their status as school-going children with CF, the responses of the older participants appeared to suggest that discussion of the matter is not particularly problematical due to their having already formed certain opinions in this regard. Therese, for instance, although less expansive in respect of this question relative to others, was clear about her position: *'It doesn't bother me ... what way [people] see me doesn't really bother me'* (P1, 28). Her rationale was as follows: that of the two categories of people to be taken into account, those who know her will judge her but the large number of people who don't know her will not judge her, so why worry? Significantly, however, she added: *'I have my friends and family and they mean the world to me and ... once I have them I don't really care what other people think'* (P1, 28). In other words, she has formed the opinion that she can afford to ignore the views of others because she has very special friends and family members on whom she can depend for positive feedback and every manner of support.

Pauline also responded as follows: *'It doesn't bother me'* (P2, 16). However, it would appear that she had adopted this position because she doesn't want to *'act as if ... it's a big problem like [that she has] this [CF]'* (P2, 16). Her candour in relation to not wanting to give the impression that having CF represents a considerable challenge was welcome; it was also rather enlightening in that it revealed the probable motivation behind her subsequent statements on this matter. For example, she stated that she doesn't *'want a fuss ... about it'* (P2, 16); that greater communication between her medical team and her local school team would be unhelpful as *'it would make a difference'* (P2, 16). In this regard, she appeared to signal a particular concern that enhanced interaction between these teams might result in additional information for her school. Indeed, she repeatedly stated that she was of the view that her local school team didn't require additional information. It is, perhaps, not surprising that she should espouse such a standpoint

given that the possession of additional information by her school would be unlikely to enable her to continue to play down the significance of having CF. It could also render it more difficult for her to make light of her absences due to illness, episodes which she appeared anxious to justify in the context of school. In effect, it is conceivable that she had a concern that the outcome of enhanced interaction between the above teams could result in a loss of control, on her part, in relation to matters over which she felt she currently has some influence (cf Deci and Ryan, 2000 on the need for autonomy being a basic human need). Again, her repetition of the following statements applies: *'... I can deal with it ... I can deal with it myself'* (P2, 17).

**Gateway to achievement of goals**

When asked to indicate whether going to school was important to them, the dominant theme in the responses of both sets of participants was the significance of school generally as the gateway to the achievement of one's goals, a finding confirmed in the literature relating to children with chronic illnesses (Foley *et al.,* 2012). Indeed, there was remarkable unanimity among the participants with regard to the potential school provides for the realisation of one's ambitions. At the same time, though unsolicited, each participant also raised the matter of nonattendance at school and of the consequence of same. In a word, they all suggested that not going to school could hamper the achievement of one's goals.

That the identified goals were relatively modest in the case of the younger children was not surprising: to learn and to make friends could conceivably function as objectives for children of comparable age across the globe. That the suggested consequences for nonattendance essentially involved poor achievements was equally unremarkable. More worthy of note is the fact that these participants did not refer to their illness or to related matters in their responses. This would appear to suggest that they are, in the main, content with their accomplishments in school to date, despite having CF and that, perhaps as a result, they do not foresee the potential that their medical condition may have to impede the fulfilment of their aims, whether modest or otherwise.

The older participants revealed higher aspirations: to do well (Therese) and to be able to do well (Pauline). From the outset, they impressed as acknowledging their identity as school-going children having CF, though in the case of Pauline same could be described as minimal. However, it could also be portrayed as in line with her strategy, already noted above, of maintaining an

identity as a regular student in school. For example, she appeared to have one fundamental objective: the achievement of academic success. In this context, she presented as particularly exercised about the upcoming Leaving Certificate: *'Like it's my Leaving [Certificate] coming up so ... I just want to do well so I can get a good Leaving'* (P2, 18). That she should focus so intensely on that examination is understandable given her stage of schooling and its significance in the Irish education system as the gateway to additional success. Hence her next statement: *'I can be able to go on and do whatever else I want to do'* (P2, 18). Her ultimate goal is to *'be happy with what [she has] done'* (P2, 18). Notwithstanding such ostensibly laudible but conventional aims, the issue of her illness and of its effects clearly cannot be ignored. For her, missing school due to CF is a particular irritant. Admitting to periods of absence *'in first, second and third year'* (P2, 18), which were represented as primarily affecting her contact with friends, an issue for chronically ill children generally (Foley *et al.,* 2012), she appeared to also suggest an impact on her stated ambition to do well. Therefore, going to school is important to her and she *'wouldn't like not want to be in school'* (P2, 18).

Therese had two key aims. The first essentially concerned her parents: she wants to *'prove'* to them that she *'can do it like ... that [she] can do well'* (P1, 29). Ever appreciative of their steadfast support for her throughout difficult times and aware of their confidence in her ability to succeed, Therese came across as strongly motivated to *'show'* them that she does *'really want to do well'* (P1, 29) notwithstanding the obstacles which may lie ahead. It is as if she is being propelled to achieve her potential, in educational terms, on foot of the commitment and care which she enjoys thanks to her parents. Her second aim was more personal and not uncommon among chronically ill adolescents (Lannon Palmer and Boisen, 2002): she wants to have a career and a family because *'in the end [she wants] to have a future'* (P1, 30). That she should articulate such an objective suggests a certain optimism with regard to same. However, her ultimate goal is to have a regular existence: to live an ordinary life and when 'older' to have the benefit of the experiences which ordinary people enjoy. Her concluding remark provides an apt summary of her views on this matter: *'I don't want anything to change for m*e' (P1, 30). However, not being able to go to school due to ill health worries her (cf. Foley *et al.,* 2012) as she doesn't *'like falling behind'* (P1, 29). As in the case of Pauline, going to school is important to her and she doesn't *'want to be missing school'* (P1, 29).

### 5.2.4   Research Question 4: What does the future mean to you?
####     Domain 4: The Impact of CF on the Children's Sense of the Future

**Specific Careers**

When invited to describe themselves as they would really like to be, as they see themselves in the future, the early adolescents revealed a tendency to focus on specific careers with which they appeared to be able to identify: hairdresser, make-up artist (Celine); architect (Louis). While naming these occupations, they impressed as having but 'kind of' considered their futures and as having but relatively superficial concepts of their futures, e.g. *'But I'd also like to do something with horses and dogs'* (P3, 19); *'I don't know really ... I'd like to have a good job'* (P4, 11). However, they willingly tackled this topic and appeared to find the task rather pleasing. Indeed, they had no hesitation about admitting to harbouring notions relating to the ownership of certain material assets: *'I'd like to ... have my own salon'* (P3, 20); *'Ah ... I'd like to see myself driving in a very smart car'* (P4, 11). Interestingly, Louis, while uncertain about the latter, nevertheless presented as enjoying this particular vision of himself in the future: *'Anyway, that might not happen'* (jolly here; P4, 11). Again, these participants did not mention CF at this juncture.

**The generic self**

The responses of the oldest children to the invitation to describe themselves as they would really like to be, as they see themselves in the future, revealed a tendency to focus on a more generic concept of self with which they aimed to identify. This includes such elements as obtaining the Leaving Certificate, achieving admission to college and securing gainful employment, aspirations already acknowledged above. While it was encouraging to hear these participants voice such ambitions, however standard, they impressed as less than enthusiastic about this general topic. Pauline actually stated that she hadn't *'really thought past [her] Leaving Cert'* (P2, 19), that her main priority is *'to be healthy ... and be well'* (P2, 19). That she should place such emphasis on 'just' wanting to be in good health suggests a certain sensitivity regarding her illness and its potential to impact on her future. Given the lack of role models, particularly for older children having CF, it is not perhaps surprising that she should adopt such a judicious approach to this subject. Therese would like to travel *'around the world ... just to see all the sights and places like'* (P1, 30) but appears conscious of the fact that her mother may benefit from advance warning in this regard, presumably for medical reasons. Again, stating that her ultimate goal is to *'settle*

*down and just be happy'* (P1, 30), it is difficult not to sense a particular awareness on her part of her true situation and, consequently, of what the future may hold in her case.

**An educational process**

On being asked how they think they will succeed in realising their future identities, as already outlined, the early adolescents focused largely on the educational process involved in the short-term, e.g., attending school, getting the relevant points at Leaving Certificate level. That she is not particularly enthusiastic about this process was evident in the case of Celine who proclaimed a certain obligation in relation to both of the above: *'I have to go to school anyway, and … I have to stay … to do Leaving Cert'* (P3, 21). It is possible that her aforementioned difficulties regarding school work may explain such responses; they may also explain her apparent enthusiasm regarding college and participation there in more than one course, following the example of a cousin. Louis concentrated on the issue of quality and seemed to link access to a high quality educational service with the realisation of his preferred future identity. In this regard, the critical elements in his view appeared to include admission to *'a really good secondary school'* (P4, 12), the opportunity to study subjects he likes and access to teachers who will help him and tell him 'stuff'. However, he also acknowledged his own role in the process: *'I think it's all up to me as well'* (P4, 12). Impressing as ambitious and shrewd, he confined his remarks to more immediate and attainable goals; he also focused on a period of time when he could reasonably expect to be in a position to put in the kind of effort, at a personal level, to which he appeared to be referring. Neither participant referred to CF when responding to this question.

**Coping with challenge**

When questioned as to how they think they will succeed in realising their future identities, the late adolescents focused on the challenges they faced in this regard. In both cases, the challenges to which they referred related directly to the upcoming Leaving Certificate examination. In other words, the key element from their perspective is a 'good' Leaving Certificate. However, that achievement of such an outcome in the context of CF may not be easy appears to bother them. For Pauline, the concern is to *'be able'* (P2, 20) to do it. In this regard, she clearly also has academic issues, needing grinds in Mathematics and Physics. In sum, managing the entire enterprise is rather demanding. For Therese, the list of concerns is as follows: that she is feeling stressed; that because her stress is *'related to sleeping and not sleeping and just … [being]*

*constantly on the go'* (P1, 32) she has to be hospitalized approximately every four to six weeks; that such admissions will continue over the next two years; that knowing that she is and that she will be *'missing school is making [her] ten times worse'* (P1. 31). In the circumstances, that she should conclude that her situation is difficult is undoubtedly justified: *'it's hard like. When I come home from school at four o'clock I'm just wrecked tired and ... sometimes ... I don't even feel like eating because I'm so tired and I'm just ... not well which doesn't help'* (P1, 32).

**Lack of commitment**

The query regarding their reasons for thinking that they will realise their chosen future identities revealed a lack of commitment on the part of the younger children in relation to those identities. Celine, for example, while initially talking about always having liked her particular choices, suddenly seemed less certain about these same choices: *'when I get older ... when I get to my Leaving Cert ... what I want to do will probably change'* (P3, 22). Moreover, she proceeded, through what impressed as nervous laughter, to select a career which she had not previously mentioned: fitness instructor. That this option was promoted not only because she likes sports but also because *'it would be good too for the CF'* (P3, 23) suggests both a recognition that her illness will remain a feature of her life into the future and that she will have to *'keep making sure ... [that she would] ... be keeping [her]self fit'* (P3, 23). It is also possible that this may truly represent her most desired option, hence perhaps the giggling episode; whether or not it represents her most responsible and/or realistic career choice is another matter.

Louis did not mention his chosen future identity but seemed to suggest that he will realise his goal because he tends to take responsibility for such matters himself: *'I mean I try to do like as best as I can do'* (P4, 12).

**Collective strength**

On being questioned about their reasons for thinking that they will realise their chosen future identities the dominant theme in the responses of the late adolescents was that of a collective resolve in respect of this objective. Firstly, there is the matter of their personal contributions: her strength and happiness (Therese); her willingness to change subjects at school and to 'push' herself to get a good result in her new subject (Pauline). Then, there is the input of loved ones: her mother in particular and also those people who care about her (Therese); her mother and Anthony (Pauline). Both participants presented as rather positive about their respective support

structures.  They also appreciate this support.  As Therese put it in relation to her mother's input: *'I need her to be like that.  Other than that I'd just be, not feeling sorry for myself but just kinda ... not putting the effort in'* (P1, 33).

Pauline described her mother and Anthony as *'very good'* (P2, 22).  It would appear that they 'sat' her down, helped her to identify her strenghts and encouraged her to set more ambitious goals based on her strengths.  In this regard, neither participant impressed as possessing the attitudes, commonly attributed to adolescents, towards their parents.

**Lack of exploration**

The youngest children revealed a distinct lack of exploration in their responses when questioned as to how they decided to choose their future identities.  Pauline, while failing to specifically mention any of her previously identified career choices, seemed to suggest that in choosing her future role, she will have to factor in her on-going need for physiotherapy.  In other words, her status as a person having CF is likely to influence her decision.  While this may signal a very relevant focus for her exploratory work, that the latter appears to be negligible, perhaps as a consequence, cannot be ruled out.  Louis, on the other hand, appeared not to take CF into account as he made no reference to it in his reply.  Talking, again, about architecture he seemed to link this choice with an interest in building and drawing.  However, he provided no evidence of having explored other related options, either independently or with others.

**Exploration**

When asked how they decided to choose their future identities, the theme of exploration emerged in the responses of the late adolescents.  In both cases, this included a number of common elements: consultation with significant others at school and at home, periods of practical work experience and examination of curricular options.  What appears to differentiate these participants is the issue of CF.  For Therese, this emerged as a key element in the decision-making process.  Having always wanted *'to work as a primary school teacher'* (P1, 35) because she loves *'working with with children ... with people'* (P1, 35), she did some work experience in her local primary school but got really ill on the fifth day having *'picked up bugs off the little kids'* (P1, 34).

The learning from that placement was significant: that she should work in an environment which does not involve 'interacting' with people.  While this 'bothered' her at the time and contributes to her current lack of decisiveness in relation to a future career, she nevertheless now believes that *'something to do with renewable energy is quite interesting'* (P1, 35) and that she is poised to fulfil the relevant third level requirements.

Pauline, on the other hand, does not give the impression that her status as a person having CF had any bearing on her decision to work in the IT area.  In this regard, she appears to credit Anthony with having provided her with the necessary encouragement and support.  However, that she is very aware of her medical condition but chooses not to refer to it in certain contexts must be borne in mind at all times.  In the circumstances, it may not be a coincidence that she seems to be choosing a career which has the potential not to involve a great deal of interaction with people; importantly, it is, of course, not accidental that she seems to have *'a good talent there'* (P2, 21) and to like the area as well.

**Being cautious**

When invited to indicate whether they had another plan in the event that things did not work out as originally envisaged, the early adolescents revealed a degree of caution in their responses, albeit for different reasons.  Both clearly lacked alternative plans but took care to appear as constructive as possible: *'But ... I'm ... happy ... I'll think of something'* (P3, 24); *'if that doesn't work out that's fine.  I'd be something else'* (P4, 14).  However, Celine appeared to entertain a genuine wariness about having a definite strategy in relation to the future.  In this regard, she impressed as content in the knowledge that she has 'something' in mind and as inclined to subscribe to the view being promoted in a friend's birthday card: *'forget the future you can't predict it'* (P3, 24).  The maxim that one should 'take each day as it comes' perhaps describes the approach being adopted by Celine (cf. also Sartain, Clarke and Heyman, 2000), no doubt for a variety of reasons.  Louis, on the other hand, seemed wary of departing from his specific strategy and of submitting an alternative proposal for his future, impressing instead as being genuinely interested in architecture: *'I'd really like to do being architect'* (P4, 14).  His nervous laughter at this juncture, plus the tentative nature of his fresh proposal, appeared to signal a general lack of ease around the suggestion that he 'might' become an engineer.  Furthermore, that he could only attribute his interest in this career to an opportunity he once had to play with what resembled a remote control car was somewhat unconvincing.  Nevertheless, he willingly applied himself to

this task, at my request and I am confident that he will 'be something else', if necessary, in the future.

**Being vulnerable**

On being asked whether they had another plan in the event that things did not work out as originally envisaged, the theme of vulnerability emerged in the responses of the oldest children. Again, both clearly lacked alternative plans. In the case of Therese, this situation appeared to be linked to some discouraging experiences in her life thus far, e.g., not being able to pursue her preferred plan; being struck down by an unusual and rather severe bout of illness which resulted in her becoming *'so sick and ... actually basically for a month [being] out of it'* (P1, 37) and in intensive care. Aware of her susceptibility to set-backs and openly admitting to being *'scared ... a lot'* (P1, 37) by such happenings, that she should perhaps be reluctant to devise back-up plans is understandable. However, that she should conclude on a positive note is encouraging: *'But ... I think ... I'd just keep trying. I wouldn't give up ... I'd just keep trying different things until I got where I wanted to go'* (P1, 37). In contrast, Pauline appeared not to want to pursue this topic. Having previously disclosed many episodes of ill health and a desire not to have her medical condition highlighted, she would only say that she hadn't considered how she might handle a set-back: *'I don't know. I haven't really thought about that'* (P2, 23).

**Being ambivalent**

The early adolescents, when asked whether they think about the future, were somewhat ambivalent in terms of their responses. Celine, for example, appeared to have difficulty deciding on an answer. *'Not really'* (P3, 25), her initial reply, has an indefiniteness about it which may suggest that to categorically rule out all thought of the future on her part may be incorrect. On the other hand, having proceeded to state an unambiguous *'No'* (P3, 25), she then seemed to pull back a little concluding with a relatively dismissive *'Nah ...'* (P3, 25). However, that she tends to *'kinda ... go with what goes on ... see what happens'* (P3, 25) would be consistent with earlier data in respect of Celine and would probably represent her overall approach to the future quite accurately. Louis appeared, at the outset, to judge that he only thought about it infrequently: *'occasionally ... yeah ... occasionally'* (P4, 15). The tentative nature of this statement suggested both a focus on the future as a generic concept and little regular contemplation of same. However, on reflection, he seemed to single out an aspect of the future which he 'definitely'

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considers: the forthcoming move by his class from the primary system to the second level system. This issue would appear to be regularly discussed at school. Thus, while he is doubtless willingly engaging, presumably both at home and at school, in discussions about the future in the context of transitioning to second level education, other more wide-ranging issues receive scant attention at most.

**Being strategic**

When questioned as to whether they consider the future, the responses of the oldest children revealed a degree of strategic thinking in relation to it. In the case of Therese, this involves a strategy which she had not previously disclosed: the separation of her future as a regular student from that of a person having CF. As regards the latter, while she thinks about it she doesn't like doing so as such a future entails difficult issues: *'how much [she's] going to deteriorate ... if [she's] going to get worse ... and how fast [she's] going to ... go downhill'* (P1, 38). Admitting to worrying about these matters, she is conscious of the fact that *'a lot of people say ... the older [one gets] the worse it gets'* (P1, 38). Thus, it would appear that she tries to curtail her thoughts about her future in the context of CF and, therefore, her potential to *'just bring [herself] down'* (P1, 38). That such efforts do not seem to be necessary in the case of her future as a regular student, however, was also evident, as she did not appear to have any constraints in relation to thoughts about school. Her entire demeanour, at this juncture, signalled a quiet confidence in relation to school. Nevertheless, it would appear that by acknowledging her needs and managing her thought processes, she alleviates her anxiety in relation to her overall future, whilst at the same time remaining open to discussion of all aspects of it, as required.

In the case of Pauline, the strategy is not to think about the future: *'it's not something that I think about'* (P2, 24). The unequivocal nature of this statement suggested not only that it referred to her future as a whole but also that it included not discussing the future, if at all possible. However, when specifically questioned about her future in the context of school and whether she thinks about this, she provided the following information: *'Yeah ... that but that's as far as I've gone'* (P2, 24). The only additional piece of information related to college: *'I want to be able to go to college and that'* (P2, 24). In other words, her thoughts in respect of the future encompass school and being admitted to college; that she doesn't go beyond this is reiterated: *'nothing really past that'* (P2, 24). In the circumstances and given her earlier pronouncements regarding not

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wishing to make 'a big deal' of her illness, it would appear that Pauline doesn't either think or talk much about any aspect of her future.

**Distance**

When invited to suggest what they mean by the future, the theme which emerged among the youngest children was that of distance. In the case of Celine, it denotes a time when she is older and has *'that job'* (P3, 26). In this regard, it appears to represent possibility and positivity: a time when she might *'have a job that [she'd] like doing'* (P3, 26). The critical element, in her opinion, seems to be job satisfaction. To work merely for monetary rewards would not appear to appeal to her. In general, Celine impressed as looking forward to this time but as lacking interest in specifying when it might materialise. Louis, on the other hand, considered this aspect from the outset, settling for *'ten years time'* (P4, 15), which, given his youth, could also be described as in the distance. Nevertheless, that it symbolises both anxiety and curiosity for him is evident from this description of what it means to him: *'something that I ... I don't want to think of ... like too often, be too worried about ... but I also kind of wanta think a bit about'* (P4, 16). Thus, it represents, at a minimum, a complex concept which, though referring to potentially difficult but essentially far-away matters, would seem to attract and possibly to require a measure of attention in the interim. In the circumstances, it is difficult not to conclude but that, for Louis, this future time includes CF and that this reality may overshadow any excitement he may feel in relation to becoming an architect or an engineer.

**Proximity**

When asked what they mean by the future the theme which emerged in the responses of the late adolescents was essentially that of proximity. This suggests that the future for these children has an immediacy about it, that it denotes a time that is not very far away. However, these participants adopted rather different approaches to this question, Therese being quite forthcoming in relation to it and Pauline being remarkably unforthcoming, albeit also ostensibly unruffled. For Therese, the future appears to signify a type of existence which she doesn't currently enjoy but for which she is 'aiming': *'It's the future that I want to have ... It's what I want to do when I'm older and when I'm an adult like'* (P1, 39). On being asked about the time-frame she had in mind, she replied *'about 5 years'* (P1, 40), a prospect which suddenly seemed to frighten her (cf. also Abbott, 2009) as she immediately stated: *'it's scary when you talk about it like that'* (P1, 40). In this regard, it would appear that it was the proximity of the impending changes, however

welcome, to her present way of life which seemed daunting: the realisation, primarily, that relatively soon, she would leave school and go to college.  This latter reality appeared to conjure up a number of additional concerns: whether or not this will involve leaving home; how her mother will react; how she herself will cope.  As she reflected on these matters, she seemed less certain about her ability to survive away from home.  There is also the problem of her developing antipathy even towards overnighting in friends' houses, a phenomenon which appears to puzzle her as she *'used to stay in everyone's house whenever'* (P1, 42).  While not mentioning her illness, it was diffficult not to sense the spectre of CF as a potential barrier to the achievement of her ideal future, the more deeply Therese delved into the details.  That she seems enthusiastic about a different lifestyle, despite her medical condition, is encouraging; however, that she may be afraid of change, given this same condition, appears undeniable.  Furthermore, not discussing this aspect of her future with her mother, as *'she'd be trying to keep [her] at bay'* (P1, 41), suggests a real concern on her part that her illness may have to be taken into account when choosing a college in a particular location.  In sum, what Therese means by the future is unclear; what is clear is that she is not looking very far ahead and not, as yet, talking about the issues with the significant other in her life, her mother.  As regards Pauline, the only comment which she was prepared to make regarding the future was to confirm its proximity, that it means the next few years.

**Happiness**

The query relating to what is important about the future for them uncovered happiness as the central theme in the responses of the early adolescents:  *'that I enjoy it anyway … just … enjoy it'* (P3, 27); *'being happy'* (P4, 16).  However, both participants appeared to link the concept of happiness with wellness.  In the case of Celine, the latter seems to primarily imply taking care to continue with her physiotherapy: *'and that I don't just forget about the physio and stuff because I won't be well if I don't continue on with that'* (P3, 27).  The clear suggestion here is that she equates being unwell with being unhappy and that the imperative, therefore, into the future, is to adhere to her physiotherapy regime, despite the associated difficulties.  For Louis, the concept appeared to be broader than just *'being healthy'* (P4, 16).  In this regard, he specifically mentioned *'earning a living kind of'* (P4, 16) and being 'independent' as markers of happiness. In other words, he seems to equate happiness with quality of life as distinct from mere good health and to perhaps imply that the realisation of such happiness is likely to involve a range of challenges into the future.

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**Achievement**

On being questioned a propos what is important about the future for them the dominant theme in the responses of the older children was that of achievement. For Therese, this appears to signify two related concepts: reaching her goals and then fulfilling them. In this regard, she was clear that the goals in question were health-related. Thus, it would seem that the imperative for her into the future is to have good health and then *'just to stay healthy'* (P1, 43). In the context of her particular illness, she identified her CF goal as *'to stay strong and take [her] meds'* (P1, 44). However, staying strong would appear to be quite a challenge and continuing to take her medication equally demanding given the rather tenuous link between both from her point of view. This has transpired largely because of her knowledge of the outcomes for others having CF who always complied with their medical regimens. These children all *'passed away … so many people that [she has] been friends with'* (P1, 44). Moreover, that a particular female friend for whom *'so many people said prayers'* (P1, 44) also failed to survive, despite consistently adhering to her medical regimen, seems to really concern her. Recalling a conversation with her mother following that girl's passing, during which she disclosed her anxieties in this regard, she added that her mother's advice was unequivocal: *'she said to me if you want to do well and you want to stay well you need to do it [to take your medication]'* (P1, 44). In the circumstances, it is relatively easy to appreciate why Therese considers that reaching her goals and then fulfilling them should represent achievement and probably the key imperative for her into the future.

Pauline, while again not very talkative, nevertheless also revealed an achievement orientation at this juncture: *'I want to be able to do well and have a good life'* (P2, 25). Having paused, she proceeded to contribute the following regarding what is important about the future for her: *'just being able to … have a good life'* (P2, 25). That she should desire success is not unremarkable; however that she should use the word 'able' in this regard in many of her responses suggests a fundamental, albeit generally undeclared, concern regarding her physical ability across a range of areas. While it would appear that to realise a 'a good life' indeed denotes the imperative, into the future, in her case, her rather circumspect approach to same suggests that such an achievement may not be easy to realize.

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### *5.2.5* *Research Question 5: How is life for you?*
### Domain 5: The Impact of CF on the Children's Sense of Life in General

**Acknowledgement**

When invited to specify what is good about their lives, the theme of acknowledgement emerged in the responses of the younger participants. In this regard, both children readily recognised their friends and family, in that order, as key to what is good about their lives. Interestingly, however, while Celine simply identified these people, Louis referred to *'having lots of … friends, lots of family'* (P4, 17). That he should formulate his reply in such terms may suggest that the number of individuals in these categories also matters, in his view. Given the nature of CF, it is no doubt helpful, both emotionally and practically, to be in a position to count on more than a few persons, if necessary. Some additional material was introduced, separately, by these children. For example, being able to *'enjoy life like'* (P3, 28) appeared to be relevant in the case of Celine and consistent with other statements made by her to this effect. Moreover, to have a hospital which she likes and nurses who are 'nice' also seem to make a positive difference and to matter to her; she appeared to suggest that she would have a difficulty with a medical team which she felt showed little interest in her. That she should proceed, at this point, to clearly state that she doesn't *'love school'* (P3, 29) was quite intriguing. It suggested that she doesn't acknowledge her experience at school as representing what is good about her life. Indeed, it would seem that she disagrees with the age-old saying which proposes that one's school days are *'the best days'* (P3, 29) of one's life. However, she attends school because she knows that she has no other option in this regard. Louis, on the other hand, specifically mentioned *'having good education'* (P4, 17) as contributing, in constructive fashion, to his life. That he appears to accept the value of a good education is evident from previous statements on his part about wanting to transition out of the primary system into a 'good' second level school. He also conceded that *'the care'* (P4, 17) he receives has a bearing in this context, though he didn't elaborate in relation to same, keeping characteristically restrained in respect of such issues. Finally, he clearly loves his neighbourhood as his initial thoughts in relation to this entire subject were: *'living in such a nice place'* (P4, 17).

**Appreciation**

When asked to indicate what is good about their lives, appreciation emerged as the main theme in the responses of the late adolescents. While the substance of their replies was essentially similar

to that of the younger participants, it was their sense of gratitude towards the significant others in their lives which really impressed me.  In this regard, Therese seemed to give equal emphasis to those closest to her: *'what's good about my life is my friends and family ... that keep me going and ... make me feel like ... myself'* (P1, 49).  Obviously, being enabled simply to persevere and to have an authentic identity matter and it would appear that having a network of intimate, supportive individuals facilitates same.  In the case of Pauline, it was her family, inclusive of her extended family, which was prioritised for admiration: *'I've a really good family.  Like my mam and Anthony ... and Joseph ... my brother ... They're always there'* (P2, 27).  This concept of having people on whom one can always depend was revisited in her comments about her extended family: *'And then my nanny and grandad ... they're brilliant .... they're always there as well'* (P2, 27).  Pauline impressed as valuing the stability of the care and attention she receives and which she regards as contributing to the positive elements of her existence.  However, she quickly moved to include the input of her friends: *'my friends as well ... I just, I love them ... they're so good and we're all so close'* (P2, 27).  Clearly, her friends are not only responsible for a beneficial, hands-on effort to make her life more pleasant, as admitted by Pauline on a number of occasions but they also seem to provide a degree of emotional support to her, such that she has become genuinely attached to them.

That she has a 'second family' in her medical team was highlighted by Therese.  Using terminology similar to that used to describe her immediate family, she talked again about being helped to just carry on: *'they kinda ... keep me going'* (P1, 49).  She also disclosed some of the other elements of her relationship with the nurses and doctors in her hospital which play a role in making her life good: the fact that she is on first name terms with them, that she can talk to them and have fun with them; in sum, it is the fact that *'they treat [her] like [a] normal'* (P1, 50) person.  Such treatment not only makes it possible for her to avoid going *'down completely'* (P1, 50) but also enables her to tolerate periods of confinement in hospital: *'you wouldn't even think you were in hospital the way they go on with you ... if it comes to me staying in hospital ... I could stay there for two weeks on end'* (P1, 50).  Therese impressed as feeling safe and relaxed in hospital, a development which she appeared to welcome given her personal situation at this time: being 16 years of age and having younger siblings whose care prohibits her mother from spending much time away from home.  She concluded with some remarks about school: *'school is good ... I'm happy in school'* (P1, 51).  However, a particular drawback is promptly admitted: *'sometimes I get a bit ... down because I'm behind in certain things'* (P1, 51).  Given the stage

she is at in school and her many absences, this statement is understandable; it may also be the reason why she has been given access to a range of grinds.  That the latter does not seem to constitute undue pressure is clarified in the next statement: *'I have to say if I didn't go to school I'd probably be depressed because I wouldn't have anything to do or to work towards'* (P1, 51).  In other words, school and all that it entails matters because without goals and a purpose in life, which it appears to represent for Therese, the potential for despondency may become very real.

**Lack of enthusiasm**

The early adolescents, when asked what they would like to change about their lives, revealed a lack of enthusiasm for change in their responses.  Interestingly, this emerged despite the fact that CF did not seem to feature as an issue for Louis.  In his case, the only matter which appeared to come to mind, having at the outset indicated a lack of knowledge in this respect, was his address: *'Ah, I don't know … we could live on the other side of town'* (P4, 18).  His reason seemed clear: *'I prefer the other side of town over there.  It's kinda nice'* (P4, 18).  However, given his satisfaction with his current neighbourhood, as indicated earlier, that he should proceed to revise the above proposal was not surprising: *'but this is fine'* (P4, 18).  In truth, it would appear that his initial reaction may have been accurate, which would explain his final remark on this subject: *'I really don't know'* (P4, 18).  That his innate politeness may also have played a role at this point should perhaps not be ruled out either.  Celine began by stating that she wouldn't change anything about her life, adding: *'there isn't actually like'* (P3, 29).  Whether the latter had been appended for my benefit or as an attempt to convince herself of the veracity of the statement was not immediately obvious.  That she had the issue of CF in mind, however, became clear straight away.  In this regard, she proceeded both to raise the matter of new medication for her illness and, at the same time, without explanation, to dismiss its potential effects: *'it doesn't really make a difference … you know'* (P3, 30).  In effect, she seemed to be suggesting that since significant change in her medical condition appears unlikely in her opinion, that she has little interest in changing other aspects of her life.  Thus, as in the case of Louis above, her opening pronouncements would appear to accurately represent her views on this question at this time.  Hence, perhaps, her concluding statement: *'I don't really … think about having it.  I just, you know, get on with it'* (P3, 30).

**CF status**

When questioned vis-à-vis what they would like to change about their lives, their CF status emerged as the central issue in the responses of the older children. However, that they held different views in relation to this was not entirely unexpected. Therese essentially stated that she wouldn't really change anything about her life. As regards having CF, she seemed to believe that it has generated certain positive outcomes in her case. These include the following: the fact that, in her opinion, it has made her strong and more enthusiastic about things. She is also a happy person, a finding reported in relation to people with CF (Abbott, 2009). In this regard, she notes that '*it's not like it's made [her] unhappy 'cause ... [she's] living with it everyday*' (P1, 52). And herein lies her dilemma: the fact that '*it's a part of life and [that she has] grown up with it*' (P1, 52) means that she cannot ever know whether the aforementioned qualities, which she values, would apply to her if she didn't have CF. This is not to deny the fact that such an existence is difficult. For example, she is constantly '*sick and in and out of hospital ... and [she has] to do meds ... [and stuff that] ... none of [her] friends have to do*' (P1, 52). Nevertheless, while '*in a way ... [she] wouldn't like to have it*' (P1, 51), on balance she wouldn't change her life though she accepts that many probably would. This applies to other aspects of her life also: her friends, her family, her medical team, her hospital. Her position regarding school was, however, less definitive: '*school ... the way school is now I'm happy. Like I'm not unhappy in school*' (P1, 52). Such a comparatively restrained comment perhaps suggests that school epitomises an additional dilemma: it is the gateway to the realisation of her purpose in life but it represents a difficult journey and one which her illness renders even more difficult. For Pauline, there was no ambiguity when asked what she would like to change about her life: '*I wish I didn't have CF ... it really is a pain to have but ... you have to just deal with it*' (P2, 29). It was clear that this query raised but one issue for her, her CF status, and that, despite her relatively few remarks in respect of it, this issue would appear to symbolise her life.

**Acceptance**

On being asked what they would wish for if they could make one wish the younger participants revealed an acceptance of their current situation. Both clearly interpreted the question as referring to their illness but apart from an initial remark by Celine that '*first of all 'tw'd be to have more wishes*' (P3, 31), they impressed as taking the matter rather seriously. In this regard, Celine repeated her desire to '*just be happy and enjoy life probably*' (P3, 31), a not uncommon attitude among the chronically ill (Heine, Proulx and Vohs, 2006). Significantly, however, she

added: *'like just to keep enjoying it'* (P3, 31). That this represents her ultimate aspiration at this time is consistent with earlier statements and a sense that she doesn't, of necessity perhaps, dare to entertain more lofty or ambitious aims; hence, her acceptance of her situation. This possibly also explains her general attitude towards the achievement of financial rewards: *'what good's money and everything'* (P3, 3). Louis, on the other hand, seemed to be accepting of his situation largely because he doesn't consider that it is altogether too bad (cf. Huyard, 2008): *'Well, I think it's ... okay having it [CF]'* (P4, 19), . This no doubt stems from the fact that his symptoms, to date, would appear to have been more aggravating than severe. Interestingly, he merely referred, at this juncture, to the annoyance of having to bring his inhaler to a sleep-over. Not referring to other adverse effects or indeed to previously mentioned concerns, he seemed content to conclude as follows: *'I don't think it affects me kind of ... it doesn't really affect me [much]'* (P4, 20).

**Being free of CF**

The query regarding what they would wish for if they could make one wish revealed that being free of CF was the dominant theme in the responses of the late adolescents. Therese was unequivocal in terms of her reply: *'My wish ... that there would be no illnesses ... at all ... not just CF like, in general ... just none ... at all'* (P1, 53). That she should produce such a reaction is not inconsistent with earlier statements given the fanciful nature of this particular question. However, this was the first occasion on which she appeared to allow herself the luxury of contemplating a life without CF. Even so, that she appreciated the make-believe quality of her disclosure is evident when one considers the totality of her wish: a world without illness or disease. Pauline was equally precise about her wish: *'I didn't have CF'* (P2, 29). She was also very clear about the reasons for such a wish: it would mean not being sick and not having to adhere to the medical regimen. In sum, it would seem that while she doesn't quite know *'what else'* (P2, 29) it might signify, she believes that *'it would change a lot of things'* (P2, 29) about her life.

# Chapter 6. Conclusions

## 6.1 Introduction

In this chapter I summarize my findings, discussing them in relation to my overarching research question and the domains of enquiry. I also reflect on my research method, outline suggested implications for practice, propose further research in this area and finally, present my conclusions.

## 6.2 Discussion of Findings with reference to Overarching Research Question and Domains

The aim of my research was to explore the identity construction of four school-going children having a diagnosis of CF with a view to establishing whether or not they consider themselves to be disabled and to have a disability. The question motivating this study, therefore, is: What kind of identity are children with CF constructing as they make their way through school?

### 6.2.1 Domain 1: What CF means to the Children (Needing Construct)

This study demonstrates that having CF for these children means that they have embarked upon a difficult journey even if they do not fully realize or accept this. It involves having to negotiate a series of challenges en route and to face ever more taxing situations as they age. The younger children described CF as a burden and a nuisance; while not particularly bothersome it nevertheless requires daily attention. In the case of the older children, CF is portrayed as more invasive and the treatment regime more onerous; it becomes necessary to engage in lengthy preventative measures as a matter of routine. Furthermore, it becomes too scary to read up about CF so not doing so and not discussing it also become necessary.

Every child appeared to accept the CF label without hesitation. In this regard, they presented as willingly identifying with a specific medical condition and complying with an individualized treatment regime. However, their talk did not embrace the personal tragedy element of the medical model approach to disability; rather, they revealed a proactive, practical approach to their

conditions which did not incorporate either a focus on cure or a sense of powerlessness due to a pathologising gaze.

### 6.2.2   Domain 2: The Impact of CF on the Children's Sense of Self  (Being Construct)

Questions relating to their fundamental identity as persons with CF seemed to take each child on an odyssey of the self, which continued throughout our meetings.   In every case, while their responses varied somewhat, the children chose similar themes to demonstrate the impact of CF on their sense of self.  The theme of difference quickly emerged in this context, though the children's views in respect of it were on a continuum ranging from feelings of difference and of abnormality, due to their conditions, to lack of certainty regarding the true meaning of normal for people with congenital impairments.  Talk about other aspects of their current identities revealed views concerning the role of CF in relation to same which varied from avoidance of any reference to it as having an effect to complete acceptance of it as having a direct role. They declared a range of sporting interests, indicating a significant focus on and level of physical activity in their lives; however, though such practice is recommended in these circumstances, it was not explicitly linked to CF by them in their accounts.  They were clear, though, that family members contribute hugely to the identity construction process, the input of friends only mentioned by two of the children at this juncture.

Having CF impacts, either directly or indirectly, on many aspects of these children's lives.  It has a significant effect on their sense of self.  These accounts indicate that the children feel abled in daily life at different times and in different contexts; they also suggest that the ideals of the ableist world are contributing to the identity building process.  However, in the absence of talk suggesting disablism, it would appear that the medical model of disability is at least being foregrounded in terms of this domain of enquiry, the children's CF identity functioning as the master identity that transcends their other identities.

### 6.2.3   Domain 3: The Impact of CF on the Children's School Life  (Schooling Construct)

The children's descriptions of their journey through school reveal a bumpy road but one which they are eager to travel as the destination, in their view, has much to recommend it.  The younger

participants reported fewer problems: little disruption, some CF-related embarrassment and regular exposure of their conditions at lunch times due to the obligation to take medication. However, they were unclear as to who knew what in relation to their medical conditions and, despite sensing a certain interest in same and a degree of pity in Celine's case, had no desire to clarify the situation in this regard. Indeed, to 'pass' as normal and to get through their school days and their school work without drawing too much attention to themselves appeared to be their focus.

The older children reported more intense situations and a greater number of CF-related difficulties. They experience considerable disruption of their academic and social worlds and require much additional tuition to simply keep up with their classmates, a substantial challenge given the requirements of the forthcoming Leaving Certificate examination. They claimed both a lack of clarity and a lack of interest in relation to others' perceptions of them: they don't discuss their medical conditions in school, keeping their identities as students separate from their CF identities; their needs are being addressed to their satisfaction; they maintain contact with their close friends even during periods of prolonged illness and absence; they have good support structures in all environments. Nevertheless, they revealed an awareness of the non-disabled gaze and a desire to influence others' perceptions of them, both through their own behaviour patterns and through control of the information in circulation regarding CF. Their primary objective is to succeed in school, an achievement which they regard as central to their life goals and which they, therefore, have prioritized, at least for the short-term.

These accounts reveal the realities of living with CF for the children, whilst also attending school; they, furthermore, reveal the relatively more demanding nature, both of their health-related and school-related circumstances, in the case of the older children. In all instances, the children appear to be attempting to paint CF into the background of their lives while at school. This is not to deny the significance of their impairments and/or their CF identities; rather, it would appear to be an attempt to prevent impairment from functioning as the defining feature of their identities, at least during school time. At other times, a focus on medical issues is presumed, indeed essential, e.g., when they have to withdraw from school and spend time in hospital. However, it is not clear that the children's efforts in this regard meet with any success. Their CF identity remains a considerable influence in the context of school, both for themselves, as their symptoms become more marked and their absences more frequent and for their

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classmates. The non-disabled gaze becomes a feature of their lives and, as evidenced by Celine and Therese, their conditions can generate at least a degree of curiosity in this environment, despite their best efforts. That said, they report supportive structures and practices in all instances, neither exclusion nor discrimination featuring in their talk. Accordingly, this study appears to suggest that the modified form of the medical model of disability applying here is still being foregrounded in the context of school; however, pointers to a social-relational model are emerging in terms of this domain though not to a significant extent.

### 6.2.4 Domain 4: The Impact of CF on the Children's Sense of The Future (Hoping Construct)

The children's talk about the future conjured up images of a road less travelled by many with their conditions and revealed a wariness on their part in relation to this issue. The early adolescents described their possible identities in terms of specific careers, focusing on the educational process ahead for them, but demonstrated a lack of commitment and of exploration in respect of their choices. While displaying caution and ambivalence in relation to the future, they chose to think of it as distant but as having the potential for happiness and a good quality of life. The late adolescents were especially guarded when talking about the future, revealing a more generic concept of the self with which they aimed to identify. From their perspective, it seems to imply significant challenge but they signaled confidence with regard to their respective support structures and an interest in exploration of their options with a view to guiding their decision-making and choosing CF-appropriate careers. However, their vulnerability was quite apparent, Pauline having remarkably little to say about this topic and Therese strategically curtailing her thoughts to educational matters. Both participants indicated that the future is upon them, a mere few years away, but were clear that it has an achievement-related quality for them and cannot be taken for granted.

The children communicated a sense of CF having the potential to exert a significant impact on their future selves. Their cautious, ambivalent and strategic approach to this topic exposed a vulnerability which was unique to this domain of enquiry. Yet, they also expressed a sense of hope in relation to it. In this regard, the younger children appeared to associate it with happiness and a good life, while the older children talked about an achievement- filled space and

demonstrated an interest in exploring possible identities for themselves in this space. It would appear, therefore, that the medical model of disability is again being foregrounded in this context, albeit with the modifications already outlined above, due to the absence of disablism in the children's talk.

### 6.2.5  *Domain 5: The Impact of CF on the Children's Sense of Life in General  (Coping Construct)*

The children in this study appear to travel through some difficult terrain but are accompanied along the way, taking each day as it comes. They acknowledge and appreciate the positive aspects of their lives: friends, family, extended family, doctors, nurses, having good education and having comfortable living arrangements. Aware of the impact of CF on their lives, the younger children are, nevertheless, not expressing a desire for a life without it; indeed, they revealed an acceptance of their situations, albeit with the caveat that same are not so bad. Pauline, however, is clear that she would prefer not to have CF as, without it, she suspects that life would be quite different. Therese suggests that having CF has generated certain positive outcomes in her case, but concludes that if she could make a wish, it would be to rid the world of all illnesses, including CF.

It would appear that, in general, the children in this study accept their CF identity and all that same entails. They enjoy considerable support on a consistent basis from a range of trusted individuals, Therese referring in this context to her second family.  There is little or nothing that the younger children would change about their lives; however, the older children would take an opportunity to be CF-free (Pauline) and to afford everybody an illness-free life if such could be arranged (Therese). Their talk is consistent with a modified version of the medical model approach to disability, though pointers to a social-relational model are evident in the context of school.

## 6.3  Methodology Reflection

I chose IPA for my research because I wanted to gain an in-depth knowledge of the children's lived experiences and I felt that this approach would enable me to access their views in a

thorough and comprehensive manner. I valued the freedom it affords in relation to the construction of questions: I could approach my topic in a non-directive but transparent fashion, allowing the children's talk to guide my thinking and to clarify the relevant issues. Being very conscious of the power of language, I decided not to use disability terminology, but to construct a set of probing questions and to adopt 'a wait and see' approach in relation to my findings. On reflection, I am very pleased about this strategy and while I accept that it may have affected my findings, I believe that it facilitated unfettered access the children's self-perceptions and life worlds.

Using IPA meant that there were few rules to be followed, either by the children or by me, once the process got underway on the day, allowing us both to interact in a relaxed and mutually respectful manner. The flexibility it allowed in terms of the interview situation itself was also important to me. Given the sensitivity of the subject matter and the potential for distress, I needed to know that the children could take breaks at any time and that their parents could be close by.

Furthermore, IPA allowed the children to talk freely about their experiences and to develop and/or to revisit issues as they deemed necessary. I sensed that they felt such an approach empowering. A limitation of this approach, however, is that it can sometimes be difficult to keep people on course and to ensure that all topics are explored, in sufficient depth, within a reasonable timeframe. I was conscious of the fact that the children were fitting these interviews in between medical tasks and that their energy levels needed to be kept in check.

The analytic element in IPA requires much time and patience. I would have appreciated being enabled to make more use of information technology from the outset but found that I couldn't really do so until well into the process. A recurring issue related to the indexicality inherent in the process: every response is open to more than one interpretation, suggesting a need for systematic attention to detail and great care in reporting of findings. In this regard, care is also required in the context of generalizability of claims due to the small number of children taking part.

## 6.4 Implications

Educational Psychologists

In Ireland, educational psychological support for students, parents and teachers is provided by NEPS, which is part of the DES. NEPS psychologists work in both primary and post-primary schools and are concerned with learning, behaviour, social and emotional development. Each psychologist is assigned to a group of schools.

A substantial body of legislation provides statutory support for education policy and provision relating to children with special educational needs. In this regard, the Education for Persons with Special Educational Needs (EPSEN) Act 2004 requires that

'A child with special educational needs shall be educated in an inclusive environment with children who do not have such needs unless the nature or degree of those needs of the child is such that to do so would be inconsistent with –
  (a) the best interests of the child as determined in accordance with any assessment carried out under this Act, or
  (b) the effective provision of education for children with whom the child is to be educated' (p. 7).

As a result of this legislation, parents, teachers and the wider community have become more aware of the policy of inclusion of children with disabilities and special educational needs in mainstream schools. In some instances, special interest groups have emerged for the purpose of highlighting the educational needs of their members, e.g., Irish Autism Action. CFI, however, focuses on enhancement of medical treatments and facilities for its members, cooperating with medical professionals and families in order to give maximum assistance to children and adults with CF. CFI does not have a remit in relation to the educational needs of its members.

The implications of this research for NEPS psychologists include the following: development of their own skill set in relation to management of the needs of chronically ill children, including those with CF and their families; support of school communities having chronically ill pupils on their registers; provision of targeted assistance, including appropriate interventions, in respect of the unique and individual needs of these children, in collaboration with other agencies and bodies having a role in this area.

A key message for educational psychologists (EPs), arising from this study, is the necessity for appropriate understanding, within the profession, of the complex nature of life with a chronic illness/CF for school-going children having same. In practical terms, such understanding suggests, at a minimum, enhancement of their skill set, on the part of EPs, as follows:

- development of their knowledge base relating to the identity issues associated with chronic illness/CF and disability;
- expansion of their professional capacity to grow positive identities among the chronically ill and those having CF;
- progression of their standard systems to include innovative procedures for the allocation of supports in respect of children with chronic illnesses/CF;
- cultivation of more self-reflective practices in light of the potentially negative impact on children with chronic illnesses/CF of the current requirement to be labeled as 'disabled' in order to access services;
- intensification of their observational, analytical and solution-focused abilities in the context of the tendency for the chronically ill and those having CF to pursue normalization and information management strategies in the effort to cope with their situations;
- augmentation of their existing protocols to incorporate a focus on provision of more empowering environments, structures, interventions and, ultimately, of more inclusive settings for the chronically ill and those having CF, taking due account of their lived experiences;
- promotion of specific competencies designed to foster constructive dialogue and fresh thinking within families, schools, related disciplines and at policy level in respect of issues such as: the impact of medical diagnoses in the educational sphere; the process of special educational needs identification and categorization; the voice of the chronically ill child.

## 6.5   Further Research

Additional research is required in relation to the needs and concerns of children transitioning into third level education on completion of their Leaving Certificate. This study shows that children

with CF have ambitions in this regard but that the implications of leaving home are far-reaching, not just for themselves but also for their families.

Research is also required into the implications for staff and other students in the third level sector of the inclusion of chronically ill students into this sector.

## 6.6    Conclusions

The children in this study are constructing identities which are fundamentally embodied.  They view their impairment in medical terms.  In this regard, their lived experiences no doubt contribute to this perception.  These include a high level of contact with medical personnel, frequent and at times prolonged periods of hospitalization, regular outpatient appointments and a rigorous treatment regime which can take between one to four hours to complete each day.

However, these children do not subscribe to the negative features of the medical model approach to disability.  There is no element of personal tragedy in their accounts, no reference to feelings of loss, no anger, no mal-adjustment.  This finding accords well with the literature on CF and, especially, on congenital conditions: being born with a medical condition cannot be equated with the acquisition of one later on. Thus, the medical model in its current form is inappropriate in the context of CF and requires modification to take account of the lived experiences of people with this impairment, such as those outlined above.

It is clear that going to school exposed the children to a set of experiences which is unique to that environment and not comparable to a medical setting.  It would appear that these experiences included some elements of disablism in some instances.  This would signal a social-relational model and, therefore, the co-existence of both types of models in the school setting.  It is also apparent that the children try to compartmentalize their lives in this setting, to leave CF outside and to focus on their other identities (e.g., as students) while inside.  Again, this finding accords well with the literature in this area, the concept of stepping in and out of their disabilities being highlighted by Allan (1999), in particular.  However, given the nature of their condition and the probability of deterioration, that such a strategy may not have the same potential for children with CF, as it appears to have for children with other disabilities, cannot be discounted.  Likewise, that

these children did not appear to engage in the transgressive practices reported on by Allan (1999) may be a function of impairment type. To attempt to simply live with CF 'sometimes' may be to embrace a strategy that is inherently fragile.

In sum, it would appear that the children in this study are constructing a number of identities and attempting to use these flexibly in different contexts. Their experiences demonstrate the presence of both the medical and the sociological dimensions of disability, though not fully in the case of the former and only minimally in the case of the latter. Whether or not both dimensions are always present is not clear; furthermore, the nature of the relationship between these dimensions is not apparent.

At this stage of their lives, however, the medical dimensions of disability have huge significance for these children. Again, however, it is not clear that they consider themselves to have anything other than a chronic illness requiring a medical solution. This may be connected to the fact that they are members of the CFAI, an association having many of the features of the biosocial movements in health referred to above. Thus, it is possible that they may identify most closely with the 'biological citizens' who populate these movements. Additional research is required in relation to this possibility as it may help to clarify the situation.

Finally, since the term 'disability' did not feature in any their accounts it would appear that they do not consider themselves to be disabled and/or to have a disability. Furthermore, given that self-identification in this regard is a prerequisite in terms of the social model, it would also appear that they cannot easily be defined as having a disability. So, the question now is: are children with CF disabled? Do they have a disability?

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# Appendices

**Appendix A   Timeline**

| | |
|---|---|
| ![Newcastle University logo] | **Breda Cotter** *Psychologist* Email: breda.cotter@newcastle.ac.uk |

**May/June 2012**

- Submit Full Ethical Assessment Form to Faculty Ethics Committee
- On receipt of ethical approval from Faculty Ethics Committee, place Recruitment Advertisement in CFAI newsletter
- Agree interview schedule with supervisor

**June/July 2012**

- Recruit children who meet the criteria in the Recruitment Advertisement
- Agree interview dates, participatory conditions and general procedure with families

**July/August 2012**

- Conduct interviews
- Begin write-up of scripts

**August/September 2012**

- Conclude write-up of scripts
- Conduct analysis of scripts

**September/October 2012**

- Write up preliminary conclusions

**November to May 2013**

- Write up first draft of thesis

**June to August 2013**

- Finalise thesis and hand into Newcastle University

**Appendix B   Recruitment Advertisement**

| ![Newcastle University logo] | Breda Cotter<br>*Psychologist*<br>Email: breda.cotter@newcastle.ac.uk |
| --- | --- |

<div align="right">

**/      / 2012**

</div>

Dear Members,

I have been employed by the Department of Education and Skills as a teacher and psychologist for over thirty years. I am currently undertaking a Doctorate in Educational Psychology at Newcastle University, Queen Victoria Road, Newcastle upon Tyne, NE1 7RU.  As part of this course I am conducting a study of identity formation among school-going children with a diagnosis of Cystic Fibrosis (CF).  I have a personal interest in this subject as there is a history of CF in my family.  Ethics approval has been given for this study by Newcastle University's Ethics Committee.

In order to progress my research, I will need to conduct face-to-face interviews with a small sample of children.  These children will have a diagnosis of CF and will understand what this means for themselves and for their families.  They will have a history of schooling and will be at critical transitional points in their schooling, i.e. in 5th or 6th class and transitioning to second level, or in the Leaving Certificate cycle and transitioning to third level.  They will also be capable of communicating their thoughts and experiences, with confidence, to a researcher.

If your child meets the above criteria and if you are interested in having him/her participate in this study, please contact me, during the next fortnight if possible, at 087 9325634 for further information.  Also, please note that your child will not be identified in the study and will have the option of withdrawing at any time.

I wish to thank the CFAI for facilitating this research, the results of which may lead to greater understanding both of the influences that shape identity formation and of the factors that contribute to a well-integrated sense of identity and, ultimately, to psychological well-being among children with CF.


Yours sincerely,


_____

Breda Cotter

**Appendix C   Interview Schedule**

| Newcastle University | **Breda Cotter**<br>*Psychologist*<br>Email: breda.cotter@newcastle.ac.uk |
|---|---|

*What CF means to the Children*

Q1:     Tell me what you think CF is.

Q2:     How does CF affect you from day to day?

*The Impact of CF on the Children's Sense of Self*

Q3:     Tell me a little about yourself.

Q4:     How would you describe yourself as you really are now, as you see yourself now?

Q5:     How have you managed to become this person?

Q6:     Why do you think you are as you say you really are now?

*The Impact of CF on the Children's School Life*

Q7:     Does having CF make a difference at school?

Q8:     What would make things better for you at school?

Q9:     What do you do to make things better for yourself at school?

Q10:    How would you describe yourself as others see you at school?

Q11:    Why do you think others see you in this way at school?

Q12:    How do you feel about all of this?

Q13:    Is going to school important to you?

*The Impact of CF on the Children's Sense of the Future*

Q14:   How would you describe yourself as you would really like to be, as you see yourself in the future?

Q15:   How do you think you will succeed in becoming this person?

Q16:   Why do you think you will become the person you see yourself becoming in the future?

Q17:   How did you decide to choose this role for yourself in the future?

Q18:   Do you have another plan if things do not work out at first?

Q19:   Do you think about the future?

Q20:   What do you mean by the future?

Q21:   What is important about the future for you?

*The Impact of CF on the Children's Sense of Life in General*

Q22:   What is good about your life?

Q23:   What would you like to change about your life?

Q24:   If you had one wish, what would that be?

**Appendix D   Participant Information Sheet**

<table>
<tr>
<td>Newcastle University</td>
<td>

**Breda Cotter**
*Psychologist*
Email: breda.cotter@newcastle.ac.uk

</td>
</tr>
</table>

/    / 2012

I am studying for a degree in Newcastle University, Queen Victoria Road, Newcastle upon Tyne, NE1 7RU.  As part of my studies, I am doing a project involving children with a diagnosis of Cystic Fibrosis (CF).   You have been selected to take part in this project.  However, it is up to you to decide whether or not you want to get involved.  I will accept whatever decision you make and share my findings with you, if you would like that, when I have finished my work.

If you agree, this means that you and I can talk about what it means for you to have CF.  I will ask you some questions and to help me remember everything you say, I will record our conversation using my tape recorder.  There are no right or wrong answers.  I am interested in your life and in what you have to say about your life.  If you do not want to answer some questions, that will be fine.  If you want to take breaks, just let me know and we can stop talking for a while.  If you want to stop the whole conversation at any stage, for any reason, we will do just that.  Your name will not appear anywhere in this study.  I will listen to the tape after our meeting and write up our conversation, leaving out your name.  When I have finished the project I will delete the material on the tape and destroy my notes.  It will not be possible to identify you or your family in the final report.

Our conversation will probably last for at least one hour.  When we have finished, I will go through the main points with you again just to make sure that you are happy about what you have said.  If, at that stage, you want to change anything or feel that other matters should be considered, we will restart the tape and include all those suggestions.

Finally, if you are happy to go ahead and take part in this project, I will call to your home and we will have our conversation there.  Before we start, I will read through this sheet with you and answer any questions you may have about this study.  I will also read through the enclosed Consent Forms and ask you and your parents to sign them.  Your parents will stay home while we talk in case we need their help or advice.

I will, of course, always be happy to answer any questions you would like to ask me about this study.


_____
Breda Cotter

**Appendix E   Consent Form (Participants)**

| | Breda Cotter |
|---|---|
| Newcastle University | *Psychologist* |
| | Email: breda.cotter@newcastle.ac.uk |

**Please read the five statements below and tick the 'Yes' or 'No' box after each one.**

| | Yes | No |
|---|---|---|
| 1.  The Recruitment Advertisement has been discussed with me and I understand it. | | |
| 2.  I have read the Participant Information Sheet with Breda Cotter and I understand it. | | |
| 3.  I have asked all the questions I can think of and they have been answered for me. | | |
| 4.  I know that I can stop, ask more questions, or make suggestions at any time. | | |
| 5.  I am happy to take part in this study. | | |

Name (Participant) :_____(Block Capitals)

Signature: _____

Date: _____

Name (Researcher) :_____(Block Capitals)

Signature: _____

Date: _____

**Appendix F    Consent Form (Parents)**

| | | |
|---|---|---|
| ![Newcastle University logo] Newcastle University | Breda Cotter<br>*Psychologist*<br>Email: breda.cotter@newcastle.ac.uk | |

**Please read the five statements below and tick the 'Yes' or 'No' box after each one.**

| | Yes | No |
|---|---|---|
| 1.  The Recruitment Advertisement has been discussed with me/us and I/we understand it. | | |
| 2.  I/We have read the Participant Information Sheet and I/we understand it. | | |
| 3.  I/We have asked all the questions I/we can think of and they have been answered for me/us. | | |
| 4.  I/We know that my/our child can stop, ask more questions, or make suggestions at any time. | | |
| 5.  I/We am/are happy to have _____ (child's name) take part in this study. | | |

Name (Parent):_____
(Block Capitals)
Signature: _____

Date: _____

Name (Parent):_____
(Block Capitals)
Signature: _____

Date: _____

Name (Researcher):_____
(Block Capitals)
Signature: _____

Date: _____

| | |
|---|---|
| | **Breda Cotter**<br>*Psychologist*<br>Email: breda.cotter@newcastle.ac.uk |

/     / 2012

Thank you for agreeing to take part in this study. As you know, it is about children with a diagnosis of Cystic Fibrosis (CF) and their views regarding their lives.

I am really glad that you agreed to talk to me about your life.  Your ideas and experiences will greatly help me and others to better understand what it means for a young person to have CF.  I am talking to some other children who have CF also, as I am interested in knowing as much as I can about this.

When I have carefully studied what you all have shared with me, I will write out my findings and hand in my project to Newcastle University.  I expect that this will take at least twelve months. Then I will get back to you and discuss my findings with you, if you wish.

Meanwhile, if you feel uneasy after our conversation today or wish to talk to me again about the study, please do.  My phone number is 087 9325634.  I will always be happy to talk to you and to answer your questions.

Finally, I want to thank your parents for allowing me to visit and to talk to you.  I wish you all many healthy and happy times together.

_____

Breda Cotter

**Appendix H   Risk Assessment Form (Participants)**

| | |
|---|---|
| ![Newcastle University logo] | **Breda Cotter**<br>*Psychologist*<br>Email: breda.cotter@newcastle.ac.uk |

**Read the eight statements below and tick the 'Yes' or 'No' box after each one.**

**Child's Name:** _____

| | Yes | No |
|---|---|---|
| 1.  Interview will take place in _____ (child's name) home. | | |
| 2.  At least one parent will be in the house for the duration of this interview. | | |
| 3.  Information Sheet has been posted to this family. | | |
| 4.  Consent Forms have been posted to this family. | | |
| 5.  Debriefing Sheet has been prepared for this child. | | |
| 6.  Procedure for dealing with difficulties has been agreed with parents. | | |
| 7.  Appropriate supports will be identified by parents. | | |
| 8.  Additional time has been set aside to assist family with any difficulties. | | |

Name (Researcher):_____
(Block Capitals)
Signature: _____

Date: _____

**Appendix I    Risk Assessment Form (Researcher)**

| | |
|---|---|
| Newcastle University | **Breda Cotter** <br> *Psychologist* <br> Email: breda.cotter@newcastle.ac.uk |

**Read the eight statements below and tick the 'Yes' or 'No' box after each one.**

**Child's Name: _____**

| | Yes | No |
|---|---|---|
| 1. I am looking forward to meeting _____ (child's name) and his family. | | |
| 2. This interview is taking place on _____ at_____ | | |
| 3. My husband is available to drive me to this house and to collect me afterwards. | | |
| 4. My mobile phone is charged, contains relevant contact numbers and is in my bag. | | |
| 5. My supervisor knows that this interview is taking place and is contactable. | | |
| 6. At least two colleagues know that this interview is taking place and are contactable. | | |
| 7. If feeling unsafe, I will terminate the interview and leave as soon as possible. | | |
| 8. I will seek advice and support, if necessary, after this meeting. | | |

Name (Researcher):_____
(Block Capitals)

Signature: _____

Date: _____

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**Newcastle University**

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**APPLICATION FOR ETHICAL APPROVAL OF A RESEARCH PROJECT FROM FACULTY ETHICS COMMITTEE**

This application form is to be used by **STAFF** and **PGR STUDENTS** seeking ethical approval for an individual research project where preliminary ethical assessment has indicated that full ethical review is required.

A completed version of this document should be emailed to the Secretary of your appropriate Faculty Ethics Committee in the University. *Applications must be completed on this form; attachments will not be accepted other than those requested on this form. This form has been designed to be completed electronically; no handwritten applications will be accepted.*

**Research must <u>NOT</u> begin until approval has been received from the appropriate Faculty Ethics Committee.**

**SECTION 1: APPLICANT DETAILS**

| | |
|---|---|
| Name of Researcher (Applicant): | Breda Cotter |
| Email Address: | breda.cotter@newcastle.ac.uk |
| Faculty & School: | **HASS**<br>**School of Education, Communication and Language Sciences** |
| Contact Address: | **26 Eaton Square, Monkstown, County Dublin, Ireland** |
| Telephone Number: | **Mobile: 00 353 87 9325634** |

**SECTION 2: PROJECT DETAILS**

| | | |
|---|---|---|
| Project Title: | The Journey through School for Children with Cystic Fibrosis: An Interpretative Phenomenological Analysis | |
| Name of Supervisor(s) (for PGR): | | Professor Liz Todd |
| Is this project: | Internally Funded √ ☐ | Externally Funded ☐ |
| If externally funded, please provide the MyProjects reference number:  BH | | |
| Category of Research: | Postgraduate Research √ ☐ | Staff Research ☐ |

| Is this a re-approval following a change to an existing project? (If so please attach previous form) | Yes ☐ | No √ ☐ |
|---|---|---|
| Who has overall control for the MANAGEMENT of this research? (Please provide their name and post) | Professor Liz Todd | |
| Who has DESIGNED the research? (Please provide their name and post) | Breda Cotter | |
| Who is CONDUCTING the research? (Please provide their name and post) | Breda Cotter | |

## SECTION 3: TYPE OF PROJECT

Please indicate the predominant nature of this project (mark one box only):

| | |
|---|---|
| **Questionnaire/Survey** <br><br> e.g. surveys of members of particular groups / organisations; mail out questionnaires, street surveys | ☐ |
| **Experiments** <br><br> e.g. participants completing tasks under controlled conditions, use of tasks/method other than or in addition to questionnaires/surveys | ☐ |
| **Observational** <br><br> e.g. observing how people behave in a natural setting or in a laboratory | ☐ |
| **Data-based** <br><br> e.g. the use of official statistics where individuals could be identified | ☐ |
| **Other** | √ ☐ |
| If you answered 'Other' please provide additional details. | I intend to use the semi-structured interview method. This will involve asking a number of open-ended questions (e.g. tell me a little about yourself) which I will have drawn up in advance, in consultation with my supervisor. To facilitate disclosure, should this be necessary, I will also have a list of prompt questions to hand (e.g. talk to me about your skills/interests/achievements). Again these prompt questions will have been agreed in advance. I will employ a non-directive, minimal probing approach, which will provide the children with considerable flexibility in terms of their responses and of the overall process. Towards the end of each interview, I will give the children an opportunity to amend their contributions and/or add additional observations should they so wish. I will conclude the interviews by summarising to ensure that the children's views are accurately and comprehensively recorded. |

## SECTION 4: OUTLINE PROJECT DETAILS

| Proposed date on which project or study will begin: | **May, 2012** |
|---|---|
| Proposed date on which project or study will end: | **August, 2013** |

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**Project Outline & Aims:**
Briefly describe the aims of this research as well as the main tasks (or tests) that participants will be required to complete or what use will be made of sensitive economic, social or personal data. This description must be in everyday language, free from jargon, technical terms or discipline-specific phrases. (No more than 700 words)

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This research proposes an exploration of identity formation and of the influences that shape it among school-going children with a diagnosis of Cystic Fibrosis (CF). CF is a recessively inherited disorder that affects multiple organ systems and is the most common life-threatening disorder in the Caucasian race (Wennstrom et al., 2011). However, improved health outcomes, which have been linked with early, aggressive and centre-based care (Orenstein et al., 2002), have led
to dramatic changes in life expectancy for CF patients over recent decades. While still a life-shortening and incurable disease, length of life has increased from a median survival age of 7.5 years in 1968 (Wennstrom et al., 2011) to the current situation which suggests 'a median expectancy of approximately 40 years' (Arrington-Sanders et al., 2006). Thus, in the case of those born today, nearly all survive well into adulthood. Improved survival means that more and more children are living with the daily stress of managing this illness, whilst also pursuing increasingly advanced academic studies and 'normal' lifestyles. Yet, many questions relating to the impact of the disease and of its treatment on important aspects of the lives of these children remain unanswered. Chief among these are questions relating to their school experiences. For example, little is known about their motivation to attend school and to apply themselves to their studies despite the challenges posed by their illness and its life-shortening status. There is correspondingly little information regarding their personal understandings of the purpose of school in the first instance and of their place within the system. In this context, research investigating how school-going children with CF conceptualise themselves and make school personally meaningful has the potential to contribute to greater understanding of their approach, not just to education, but to life as a whole.

The present exploration will be conducted within the theoretical framework of ego identity development, as outlined by Erikson (1950, 1964, 1968, 1985) and operationalised by Marcia (1966, 1967, 1976, 1980, 1993). It subscribes to the premise that 'a coherent, well-integrated sense of identity provides a frame of reference for dealing with questions about the meaning, purpose and direction of one's life' (Berzonsky and Luyckx, 2008).

The study will also draw on research, primarily in psychology and in the health sciences, relating to the interplay of identity and well-being. Such research clearly suggests that successful identity formation has the potential to result in behaviours and attitudes indicative of positive psychological functioning, i.e. well-being in its various forms (e.g. Marcia et al., 1993).

Accordingly, it is hypothesised that a well-integrated sense of identity among children with CF will better equip them to make school personally meaningful and will lead to behaviours and attitudes indicative of well-being. The overall aim of the study is to establish how a well-integrated sense of identity among such children might enable them both to make school personally meaningful and to achieve well-being.

To accomplish the aim, it is proposed to collect qualitative data from a small sample of children at critical transitional points in their schooling, i.e. in 5$^{th}$ or 6$^{th}$ class and transitioning to second level education or in the Leaving Certificate cycle and transitioning to third level education. This will be done via semi-structured interviews to be conducted in the children's homes. The data generated in the course of these interviews will be analysed in accordance with Interpretative Phenomenological Analysis procedures (Smith and Osborn, 2008) and will be used solely for purposes relevant to the study (i.e. to establish themes, connections, differences in the accounts). The data will be anonymised, stored in the researcher's home for the duration of the study and destroyed on its completion.

The main task for the children is to participate in the interview process. These face-to-face encounters will each take approximately one hour, though this time allocation may be insufficient depending on the level of engagement of individual participants. Other tasks include the reading of associated documents and the signing of a Consent Form (copy attached).

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## SECTION 5: PROPOSED RESEARCH METHODS

Please provide an outline, in layman's terms, of the proposed research methods, including where and how data will be collected and stored (including steps that will be taken to ensure the confidentiality of personal data) and all tasks that participants will be asked to complete. Specify if the research will take place outside of the UK or in collaboration with internationally-based

partners, and / or if research will take place using the internet. Present an outline of the method in a step-by-step chronological order, and avoid using jargon and technical terms as much as possible. (No more than 700 words)

This study is essentially designed to explore in detail how Irish school-going children with CF identify themselves and make sense of their lives. It will be carried out in Ireland. The challenge is to examine and unpick their individual perspectives on their life-worlds. In order to accomplish this, I propose to use Interpretative Phenomenological Analysis (IPA). In IPA, 'the aim … is to explore in detail how participants are making sense of their personal and social world and the … currency … is the meanings particular experiences, events, states hold for participants' (Smith and Osborn, 2008). The method is the semi-structured interview. This method permits the collection of large amounts of qualitative data and, using IPA, the generation of 'thick descriptions' of participants' experiences.

Upon receipt of ethical approval from Newcastle University, I will contact the Cystic Fibrosis Association of Ireland (CFAI)
and request that the Recruitment Advertisement (copy attached) be included in its next newsletter to members. I will talk to all respondents who subsequently contact me and confirm that their children meet the criteria set out in the Recruitment Advertisement. I will request telephone numbers from the respondents and agree to let them know, within ten days, whether or not their children will be included in the study. Then, in consultation with my supervisor, I will select four children to take part in the study and a further four to substitute for any children who may, for whatever reason, have to terminate their participation.

Having agreed the sample, I will telephone the four sets of parents whose children are to be included in the study and make arrangements to hold the interviews in their homes. (I will telephone the other parents afterwards). I will also outline the format that the interviews will follow, explain that they will be taped and point out that they are likely to take approximately one hour to complete. I will advise them of the conditions under which their children will take part in the study (see attached copy of Participant Information Sheet) and undertake to post a copy of same to them. I will then ask them to convey all of this information to their children in advance of my visit, reassuring them that, before starting the interviews, I will go through it all again with each child.

On the appointed days, I will travel to the children's homes to conduct the interviews, as agreed. I will introduce myself to the families and outline the general aims and scope of the study. I will then go through the contents of the Participant Information Sheet and invite questions. I will emphasise the voluntary nature of the exercise and the fact that the children may withdraw at any time and for any reason. I will also highlight the fact that the data will be anonymised and that it will not be possible to identify the families in the final report. Finally, I will go through the contents of the Consent Forms (copies attached) and invite both parties to provide written consent before starting the interviews.

Having obtained written consent, I will interview the children unaccompanied by their parents. This will involve following a schedule of open-ended questions which I will have drawn up in advance, in consultation with my supervisor. To facilitate disclosure, should this be necessary, a list of prompt questions will also be agreed in advance. I will employ a non-directive, minimal probing approach, in accordance with IPA procedures and I will allow the children 'a strong role in determining how the interview proceeds' (Smith and Osborn, 2008). Towards the end of the interview sessions, I will provide the children with an opportunity to amend their contributions and/or add additional observations should they so wish. I will conclude by summarising to ensure that their views are fully understood.

Following each interview, I will debrief the children and provide them with a written Debriefing Sheet (copy attached).

All the data collected on the tapes will be transcribed onto sheets of paper for analysis in accordance with IPA guidelines (no internet use). Both sets of information will be stored in my home for the duration of the study and destroyed on its completion.

## SECTION 6: PARTICIPANT DETAILS
Does this research specifically target (select all that apply):

| | |
|---|---|
| Students or staff of this University | ☐ |
| Adults (over the age of 18 years and competent to give consent) | ☐ |
| Children/legal minors (anyone under the age of 18 years) | √ ☐ |

| | |
|---|---|
| The elderly | ☐ |
| People from non-English speaking backgrounds | ☐ |
| Welfare recipients | ☐ |
| Anyone who has a physical disability | √ ☐ |
| Clients of professionals | √ ☐ |
| Anyone who is a prisoner or parolee | ☐ |
| Any groups where a leader or council of elders may need to give consent on behalf of the participant | ☐ |

| | |
|---|---|
| Estimated number of study participants: | **4** |
| Age from: | **10 years** |
| Age to: | **17 years** |
| Source and means by which participants are to be first approached/recruited: | Participants will be recruited through the CFAI.  I have already been in contact with the association and been assured of its support for my research.  I plan, on receipt of ethical approval from Newcastle University, to place a Recruitment Advertisement (copy attached) in the association's newsletter.  This is circulated to all members: people with CF, families having children with CF. Those parents interested in having their children participate in the study will be requested to contact me directly, by telephone, for further information. |

| | YES | NO |
|---|---|---|
| Does this project require approval from an external authority (e.g. LEA, school, governing body)? | ☐ | √ ☐ |
| Has approval already been granted? | ☐ | ☐ |

| **SECTION 7: PARTICIPANT INFORMATION** | YES | NO |
|---|---|---|
| Will you inform participants that their participation is voluntary? | √ ☐ | ☐ |
| Will you inform participants that they may withdraw from the research at any time and for any reason? | √ ☐ | ☐ |
| Will you inform participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs? | √ ☐ | ☐ |
| Will you provide an information sheet that will include the contact details of the researcher/team? | √ ☐ | ☐ |

| | | |
|---|---|---|
| Will you obtain written consent for participation? | √ ☐ | ☐ |
| Will you debrief participants at the end of their participation (i.e., give them an explanation of the study and its aims and hypotheses)? | √ ☐ | ☐ |
| Will you provide participants with written debriefing (i.e., a sheet that they can keep that shows your contact details and explanations of the study)? | √ ☐ | ☐ |
| If using a questionnaire, will you give participants the option of omitting questions that they do not want to answer? | ☐ | ☐ |
| If an experiment, will you describe the main experimental procedures to participants in advance, so that they are informed about what to expect? | ☐ | ☐ |
| If the research is observational, will you ask participants for their consent to being observed? | ☐ | ☐ |

### SECTION 8: PARTICIPANT CONSENT

Please describe the arrangements you are making to inform participants, before providing consent, of what is involved in participating in your study and the use of any identifiable data. (No more than 300 words)

Participants' parents will be informed of what is involved when they first make contact with me, by telephone, following circulation of the CFAI newsletter containing the Recruitment Advertisement (copy attached). If happy to have their children take part, they will be requested to talk to them about the study and about the interview process in a way that suits them. They will be asked to explain to their children that their names will not appear anywhere in the study and that

it will not be possible to identify them or their contributions. I will then agree interview dates and times with each family. I

will explain to them that before starting each interview, I will talk to their children about the study and answer any questions they may have in relation to it.

I will further explain that, before starting each interview, I will require written consent from them and from their children for

participation of the latter in the study. In this regard, I will undertake to post a Participant Information Sheet (copy attached) and the Consent Forms (copies attached) to each family and ask the parents to read through and discuss the

contents of these documents with their children in their own time. I will ask them to tell their children that I will go through all this information with them again before starting each interview. On arrival at each of the participants' homes to

conduct the interviews, I will, as agreed, talk to them about the study and about the interview process. I will also read through the Participant Information Sheet and Consent Forms with them. I will answer any questions they may have in

relation to any aspect of the study.

Participants should be able to provide written consent. Please describe the arrangements you are making for participants to provide their full consent before data collection begins OR If you think gaining consent in this way is inappropriate for your project, then please explain how consent will be obtained and recorded. (No more than 300 words)

I am arranging the provision of full consent on the part of the participants by seeking written consent from them and by involving their parents, from the outset, in the consent process. Parents will be required to give verbal consent for the participation of their children during our initial discussions. They will then be requested to discuss the study and the interview process with their children. To facilitate these discussions, I will post a Participant Information Sheet (copy attached) to each family which outlines what is involved for children who agree to participate in the study. Before

starting each interview, I will talk to the children about the study and answer their questions in relation to it.

A key condition of involvement is provision of written consent by both the children and their parents, in my presence, immediately prior to the commencement of the interviews.  In this regard, a separate consent form has been developed for each party (see attachments for copies of the Consent Form – (for) Participants and of the Consent Form – (for) Parents).  To facilitate the provision of informed written consent by each party, I will post copies of these forms to the families and request that they discuss them with their children before my visit.

Participants will, thus, have an opportunity to discuss the documentation, the study, the consent and interview process and their individual contributions/overall involvement with their parents in the first instance.

On interview day, prior to data collection, they will have a further opportunity to discuss the study with me, raise any concerns and ask questions about the research.  I will read the Consent Forms (copies attached) with them and If, at that point, both parties are willing to support the study, I will ask each to sign the appropriate form in my presence.

Please attach a copy of the information to be provided to the participant(s) to enable informed consent, this should include the 'Consent Form' & 'Participant Information Sheet' on appropriately headed paper.


## SECTION 9: PARTICIPANT DEBRIEFING

It is a researcher's obligation to ensure that all participants are fully informed of the aims and methodology of the project, that they feel respected and appreciated after they leave the study and to ensure that participants do not experience any levels of stress, discomfort, or unease following a research session.  Please describe the debriefing that participants will receive following the study and the exact point at which they will receive the debriefing. If you do not plan to provide a written debriefing sheet then please describe your alternative position. (No more than 300 words)

At the end of each interview, I will thank the participants for answering the questions they answered.  I will tell them that I value their opinions and appreciate the fact that they shared their experiences with me.  I will then go back over the general aims and scope of the study, inform them of the fact that I am interviewing other children with a diagnosis of CF, outline the remaining steps that I will have to take and indicate a likely completion date.  At that juncture, I will give them the Debriefing Sheet (copy attached) which summarises these points in simple language.  I will read through it with them and tell them that I am leaving it with them.  I will draw their attention to my mobile phone number, towards the end of the sheet and explain that I'm giving it to them should they need to get in touch with me, at any time, about any aspect of the study.  I will then invite questions and offer to answer any they may have.  I will explain that I will carefully consider all the information they have given me and reiterate that I will be happy to talk to them at any future time should they wish to revisit any of the issues discussed.  Finally, I will invite their parents to join us and I will repeat these sentiments and views in their presence.

Please attach a copy of the debriefing sheet that you will provide on appropriately headed paper.


## SECTION 10: INSURANCE & RISK CONSIDERATIONS

Newcastle University must have in place appropriate insurance cover for its legal liabilities for research studies. Dependent upon the nature of the research and how it is governed cover will either come under **Clinical Trials Insurance** or **Public Liability Insurance.** Please refer to the supplementary guidance "When does the Insurance Office need to be notified of a research proposal" for clarification.

**Potential risk to participants and risk management procedures**
Identify, as far as possible, all potential risks (small and large) to <u>participants</u> (e.g. physical, psychological, etc.) that may be associated with the proposed research. Please explain any risk management procedures that will be put in place and attach any risk assessments or other supporting documents. Please answer as fully as possible, note 'None' / 'No risk responses' are not appropriate. (No more than 300 words)

The potential risks to participants are psychological, given that they will be required to think and talk about their lives and circumstances. However, in order to minimize such risks, I will conduct each interview in the children's homes and ask parents to be available in another room, during this time, should any difficulties arise. I will highlight the voluntary nature of their participation to the participants' parents, during our initial discussions and reiterate this when talking to the children immediately prior to the commencement of data collection. I will inform the parents and, before starting the interviews, the children, too, that they may withdraw from the research at any time and for any reason. I will assure them that there are no right or wrong answers, that they have the freedom to answer only those questions they wish to answer, that they may take breaks as and when they wish and that their level of participation will not carry any consequences. I will highlight the confidentiality that they are guaranteed given that their names will not appear anywhere in the study and that it will not be possible, therefore, to identify them or their families. I, personally, wlll also take care to be on the alert, at all times, for any signs of distress, fatigue or potential difficulties. I will be guided by the parents in such situations and will have agreed this
with them in advance.

All members of the CFAI have access to a range of supports and I will be suggesting that these supports be availed of, if necessary. I will, of course, be happy to facilitate the families in arranging such support. I consider that any involvement on my part, other than as a researcher and student, would be inappropriate.

**Potential risk to researchers and risk management procedures**

What are the potential risks to <u>researchers</u> themselves? For example, personal safety issues such as lone or out of normal hours working or visiting participants in their homes; travel arrangements, including overseas travel; and working in unfamiliar environments. Please explain any risk management procedures that will be put in place and attach any risk assessments or other supporting documents. (No more than 300 words)

The potential risk to myself, in this instance, is psychological, given the history of CF in my family. However, I do not envisage any such difficulty. I regard the opportunity to conduct this study and to meet the participating families as a privilege. It is my hope that the study will contribute to the knowledge base in CF and enhance our understanding of the impact of the disease on young people. Should I feel distressed at any point, I will seek a meeting with my supervisor and follow her advice. I also have some very experienced colleagues in whom I can confide at short notice and in whom I have absolute trust.

With regard to personal safety issues, I intend to travel to the participants' homes during normal working hours. I expect to be able to recruit four children in the greater Dublin area and therefore relatively close to where I live. My husband will drive me to each house and collect me afterwards. I will have my mobile phone with me at all times.

I have many years of experience of meeting with parents and children around sensitive issues and am confident that I will handle the interviews in a professional manner. I also know when I feel safe and appreciate the importance of leaving unsafe environments at the earliest opportunity.

Please attach a risk assessment or any other appropriate documents as required.

**SECTION 11: SUPPORTING DOCUMENTATION**

Please supply copies of any applicable documents in support of your answers. Ensure that attached files have appropriate file names.

| Document | Attached |
|---|---|
| Participant Consent Form | √ ☐ |
| Participant Information Sheet | √ ☐ |
| Participant Debriefing Document | √ ☐ |
| Questionnaire(s) | ☐ |
| Outline Protocol | √ ☐ |

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| Risk Assessment | √ ☐ |
|---|---|
| Original Ethical Assessment (re-approval only) | |
| Others (please list): | |

## SECTION 12: DECLARATION

| I certify that the information contained in this application is accurate.  I have attempted to identify the risks that may arise in conducting this research and acknowledge my obligations and the rights of the participants. | |
|---|---|
| Name of Principal Investigator: | Breda Cotter |
| Signed: | |
| Date: | 09/05/2012 |

*For office use only:*

The appropriate Ethics Committee has considered the ethical aspects of this proposal. The committee recommends that the programme/project be:

☐ Approved          ☐ deferred (for reasons attached)          ☐ not approved

| Name of Committee Member: | |
|---|---|
| Ethics Committee Concerned: | |
| Signed: | |
| Date: | |