

Narratives of Young People Living with Cystic Fibrosis (CF)

REBECCA ADLINGTON

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ABSTRACT

Background and aims: Cystic Fibrosis (CF) is the most common genetic, life threatening disorder in the UK (Cystic Fibrosis Trust, 2010). Given the trajectory of the illness, adolescence may be a particularly challenging period, during which young people become more aware of differences from peers, and are faced with the task of balancing increasing illness demands with the drive to aspire to developmental goals. Nevertheless, little research specifically explores how young people with CF reconcile their illness experiences with the emerging sense of self. In an attempt to address this gap in the literature, this study sought to hear the narratives of young people with CF with reference to the local and broader contextual factors influencing their construction, with the aim to further understanding, inform clinical practice and improve support for young people with CF.

Methodology: A qualitative approach was employed. A purposive sample of six participants diagnosed with CF and aged between 12 and 16 years was recruited. Participants were asked to take photographs of their experiences of life as a young person with CF which were used alongside a semi-structured topic guide in individual interviews to explore the young person's narratives. The interviews were audio-recorded, transcribed, and analysed using a narrative approach to explore both what was said and how it was told.

Analysis and Findings: The researcher's global impressions of each person's narratives, along with details of the local context of the interview were presented. Following this, similarities and differences across the narratives were considered with particular attention to how the main storylines were interwoven with participants' emotional experiences, the identity work taking place through the narrative, and the broader narratives available to them. It emerged that (i) CF was perceived as part of participants' normality which they had grown accustomed to over time, (ii) participants drew on cultural narratives to position themselves as normal teenagers, to maintain a positive sense of self, though also leading them to minimise difficulties and distress, and (iii) participants continued to position themselves within the norm as they talked of their futures, describing similar hopes to their peers, and again played down concerns about how CF might impact on their futures. These findings are discussed with reference to the clinical implications, strengths, and limitations of the methodology, and directions for future research.

Owing to advancements in treatments for Cystic Fibrosis (CF), individuals with this illness are now expected to live well into adulthood. With improved prospects comes a greater awareness of the potential long-term psychological implications of the illness experiences of children and young people. Adolescence may be particularly challenging as young people face the task of balancing the increasing demands of illness with developmental goals, the outcome of which may impact upon social skills, self-esteem, and their developing identity. Quantitative studies in this area present a rather variable picture concerning the extent to which young people with CF are affected by their experiences. Only a handful of qualitative studies exist which attempt to explore how young people make sense of their experiences. While these offer some insight into the experiences of young people with CF and highlight the benefits of adopting a qualitative approach, they overlook the role played by local and broader contextual factors, which may influence the stories young people tell.

This study represents an attempt to explore the young person's experience of living with CF: how they make sense of their experiences and reconcile these with their emerging sense of self. A narrative approach is adopted to afford the researcher the opportunity to explore how these young people positioned themselves relative to the local and broader narratives available to them. The stories that emerged are carefully considered within the context of the researcher's background, the existing literature on CF in adolescence, and broader contextual factors, acknowledging the co-constructed nature of their narratives. It is hoped that the findings of this study may go some way to furthering our understanding of the experiences of young people with CF and inform the design and delivery of health services for this population of young people.

Chapter 1, 'Researcher's stance and literature review,' comprises four sections, which aim to: (i) introduce the researcher's position and the theoretical underpinnings of the study, (ii) provide an overview of CF including its effects on the young person's physical and psychological wellbeing and the medical and societal narratives surrounding this illness, (iii) consider the broader narratives around identity development and adolescence and the experience of adjusting to illness, and finally (iv) present the study's clinical relevance and aims.

Chapter 2, 'Methodology', initially details the epistemological position of this study and justification for the use of narrative inquiry. The research design is then presented, including exploration of the decisions behind the methods chosen to obtain and analyse the data, along with details of the

ethical considerations. This chapter closes with discussion of the steps taken to ensure trustworthiness, rigour, and credibility.

In Chapter 3, 'Findings and Discussion', the stories that emerged from the data are presented. To provide the reader with a framework in which to position the interpretations, the first half includes details of the interviews and 'global impressions' (Lieblich, Tuval-Mashiach, & Zilber, 1998) of each account. The second half presents the collective storylines emerging from the narratives, considered alongside the existing literature to ensure that the findings may be understood in the context of wider narratives pertaining to this area of inquiry.

Chapter 4, 'Conclusion', aims to articulate a response to the study's research questions. Thus, the findings of the study are initially summarised, before moving on to consider the strengths and limitations of the study, and possible avenues for future research. The chapter closes with the researcher's reflections on the research process.

1.1 MY POSITION

When conducting qualitative research it is necessary for the researcher to be open about their interest and stance on the topic in question (Emerson & Frosh, 2004). Indeed, my background and beliefs influence who I am as a researcher, and constitute a vital context for portraying and interpreting the experiences of Cystic Fibrosis (CF) in adolescence. For this reason, this section outlines how I came to be interested in this area.

Whilst working as a trainee clinical psychologist in a Child and Adolescent Mental Health Service, I received a referral for a 14 year-old girl, diagnosed with CF. She was experiencing depression and anger, which the referrer believed was precipitated by deterioration in her physical health and difficulty adjusting to the impact of CF on her life. With limited prior knowledge of CF, I engaged in further reading to gain a better understanding of how CF might influence a young person's life. Through this, I became aware of the many difficulties that young people with CF may face, as the burden of illness and treatment impacts on their physical health limiting their opportunity for close peer relationships, and engagement in activities that may encourage the development of a positive self-image. Alongside this however, I was struck by the range of differing positions and responses held by those around these young people. It seemed that the emphasis on illness and treatment which dominated the literature was at odds with that of wanting to be 'normal' and the perception of being 'healthy' that might be held by young people with CF (Lowton & Gabe, 2003; Pinder, 1996; Williams, Corlett, Dowell, Coyle, & Mukhopadhyay, 2009). I was therefore left wondering how these different narratives might influence the developing sense of self of a young person with CF.

1.1.1 Theoretical Underpinning of this Study

In my attempt to understand the experiences of young people with CF I will adopt a narrative approach (Bamberg, 2004, 2007, 2011; Riessman, 1993; Wells, 2011). This constructionist approach argues that people's identities are situated and performed through talk (Mishler, 1999). Thus through our narratives we actively construct our sense of self (Gergen & Gergen, 1997; Polkinghorne, 1991) allowing us to understand ourselves as individuals, evaluate our actions, and predict future outcomes (Atkinson, 2007). This approach also assumes that our identities are informed and constrained by the narratives that prevail within the local, historical, and cultural

context (Taylor & Littleton, 2005). Therefore the individual's narrative is recognised as both personal and social, and as co-constructed within a particular interaction. The relevance of this position to the research question is discussed further in the methodology. However, it is important to highlight at this juncture, that this position has implications for the role of the researcher in the process of narrative production (and interpretation). Indeed, as narratives are perceived as co-constructed, the researcher must 'own' their perspectives (Elliott, Fischer, & Rennie, 1999), to ensure that their unavoidable influence on the research process is clear to the reader. Thus, to make certain that the position of the researcher is transparent throughout, the first person will be used where necessary¹.

1.2 LITERATURE REVIEW

A systematic literature search was conducted over an 18-month period ensuring comprehensive coverage of the relevant topics and minimising the potential for bias. The search comprised a number of stages ranging from a generic search of the literature using key terms, to a more specific search according to inclusion and exclusion criteria (see appendix A for details).

The ensuing literature review begins with an overview of the medical narratives which inform health care provision and the experience of living with CF. This explores the epidemiology and aetiology of the illness, treatment, and the effects of the illness on the young person's psychological wellbeing. The broader cultural and theoretical narratives around identity development and adolescence, and the experience of adjusting to illness are then considered. In closing, the chapter explores the clinical relevance and aims of this research.

1.2.1 What is Cystic Fibrosis (CF)?

CF is the most common genetic, life threatening condition in the UK, affecting 1 in every 2500 children (Cystic Fibrosis Trust, 2010). It is inherited via an autosomal recessive mode (Lowe, May, & Reed, 1949)². The identification of the specific gene for CF (Rommens et al., 1989), the most common mutation of which (delta F508) accounts for over 80% of CF cases, has allowed for the

¹ This is in contrast to the third person position which is traditionally used in academic work.

² This may mean that it can be inherited by two unaffected carrier parents, one affected parent and one carrier, or two affected parents. Given that CF may make it difficult for those affected to reproduce (Stark et al., 2003), often neither parent knows they are a carrier which may have important implications for their psychological wellbeing following the birth of a child with CF (Tluczek, Kosciak, Farrell & Rock, 2005).

developmental of antenatal screening tests. Nevertheless, owing to political, ethical, and financial constraints this method of diagnosis is not as widely used as might be expected (Kerr, 2005). Thus, the sweat test (Darling, di Sant'Agnes, Perera, & Andersen, 1953), which looks for elevated levels of sodium chloride in the infant's sweat, is currently the most widely used method of diagnosis in Western society. This allows around 70% of CF cases to be diagnosed within the first year of life (Christian & D'Auria, 1997)³.

CF presents as a progressive, obstructive, pulmonary disease commonly with pancreatic insufficiency (Christian & D'Auria, 1997). Nevertheless, the clinical diversity of CF means that the onset and severity of pulmonary and pancreatic disorders varies (Kerr, 2005). CF is marked by increased viscosity of endocrine secretions throughout the body, predominantly impacting upon the functioning of the lungs and pancreas; blocking airways and pancreatic ducts. These blockages make the individual susceptible to infection and inflammation which through repetition may lead to irreversible tissue damage (Ratjen & Döring, 2003; Rosenstein & Zeitlin, 1998). CF may also affect reproductive function in both males and females, and impair heat regulation as the levels of sodium chloride (salt) in the person's sweat are elevated (Rosaler, 2007).

1.2.2 Management of CF

As a multi-system illness with no cure, CF requires complex medical management to reduce the symptoms and likelihood of infection (Badlan, 2006). This includes daily antibiotic therapy to prevent infection, enzyme supplements taken with meals, a high calorie diet, and regular physiotherapy to clear mucus from the lungs (Bluebond-Langer, Lask, & Angst, 2001). Physiotherapy is a time consuming process which it is recommended the person with CF undertakes 30 minutes between two and four times a day. Perhaps unsurprisingly, people are more likely to report difficulty adhering to physiotherapy than other aspects of the treatment regimen (Badlan, 2006), with many young people finding it difficult to fulfil their hopes of a 'normal life' because of the demands placed on them by this onerous treatment. Consequently, a trade-off between the quality and quantity of life may occur, with young people reducing the amount of treatment they are willing to undertake in favour of living what they perceive to be a more normal life (Radley, 1994).

For those with end-stage pulmonary complications, lung transplantation has become an important treatment option (Christian & D'Auria, 1999). According to figures from the Registry of the

³ Taking into consideration the date of this reference it is possible that not all those who are recruited to take part in this study will have been diagnosed at birth.

International Society for Heart and Lung Transplantation (accessed March 2012 for the period of 2010-2011), approximately 20% of all lung transplants conducted in Europe were for people with CF, more than any other category of illness except Emphysema/Chronic obstructive pulmonary disease.

Guidance on the treatment of those with CF emphasises the medical management of the illness and in particular, the course of treatment available to those who suffer complications such as infections due to CF (National Institute for Clinical Excellence (NICE); CG69, 2008; IPG 170, 2006). This places CF firmly within the medical model, with little consideration of the psychosocial needs of individuals with CF in any of the literature published by NICE. Nevertheless, guidance available from the Cystic Fibrosis Trust (Cystic Fibrosis Trust, 2011) recommends that a psychologist form part of the care team and suggests annual reviews of the psychological needs of those with CF. It also provides an overview of the potential psychological difficulties that might be encountered by individuals with CF and those around them. This includes factors related to the demands of the illness such as adherence to treatment and adjusting to diagnosis (i.e. for the parents or in cases of late diagnosis, for the person with CF) but also recognises that living with CF may lead to anxiety, depression, and low self-esteem. Consequently, the emphasis on the medical management of CF may overshadow the emotional and psychosocial needs of those living with CF and the extent to which such medical and societal narratives may influence the individual's illness experience.

1.2.3 Medical and Societal Narratives of CF

Within Western society the dominant narratives around the causation and treatment of CF are largely medical. However, changes in medical understanding of CF and greater access to online resources including others with CF has meant that those with the illness now have access to different narratives about CF. Importantly, the narratives they draw upon will influence their understanding of their illness, and how it should be managed (Smith & Sparkes, 2002).

One area in which there has been a great deal of change surrounds the classification of CF. With greater understanding of the genetic causes there has been a shift from classifying CF on the basis of its clinical presentation towards classification on the basis of mutation of the CFTR (Cystic Fibrosis Transmembrane Conductance Regulator) protein⁴. Medical professionals have thus found themselves in a position where they are *“left with the paradoxical situation of having some patients with typical CF in the absence of mutations, and others, with CFTR mutations in the absence of*

⁴ This has been accompanied by increased use of genetic testing within clinical practice to confirm/obtain a diagnosis, with approximately 95% genotyped in 2010 (Cystic Fibrosis Trust, 2012).

clinical features" (Rosenstein, 2002, p. 84). The consequence of this is greater heterogeneity in those conditions that come under the umbrella of "Cystic Fibrosis", and as highlighted by Hedgecoe (2003) a lack of consensus around whether CF is in fact a syndrome or a disease⁵. For the medical profession, this may have substantial implications for the way in which CF is talked about, treated, and researched (Hedgecoe, 2003). This introduces greater variance into the narratives around CF, as the symptoms, treatment, and illness trajectory may differ significantly across those with CF.

Advances in the understanding have also brought improvements to treatment and increases in the life expectancy of those with CF. Thankfully, no longer can it be said: "*Woe to that child which when kissed on the forehead tastes salty. He is bewitched and soon must die.*" (an adage found in European folklore, Welsh & Smith, 1995), or that CF is a "*fatal illness of childhood*" (Kerr, 2005, pp. 879). With advances in therapies the survival rate for CF has increased markedly with the median life expectancy now 34.4 years (CF registry annual data report, 2009), and those born in 2000 predicted to reach 50 years of age (Dodge, Lewis, Stanton & Wilsher, 2007; Webb, Jones, & Dodd, 2001). In addition, childhood mortality figures have decreased significantly, with a reduction in childhood deaths of 59% between 1985 and 1999 (Kulich, Rosenfield, Goss, & Wilmott, 2003). In 2009, only 3 of those who died from CF in the UK were children (CF registry annual data report, 2009).

With improved prospects for young people with CF, many now enter adolescence in better physical health, grow-up with more optimistic medical, parental, and personal attitudes to CF (Sawyer, Rosier, Phelan, & Bowes, 1995), and look forward to achieving in higher education, entering full-time employment, and establishing their own families (Badlan, 2006). Nevertheless, outdated ideas about the survival rates for young people with CF, as well as the impact it may have on their physical and psychological wellbeing continue to pervade societal narratives of CF. Indeed, a brief search of the literature readily available through the internet⁶ reveals that the information available about life expectancy varies from 31 to over 50 years of age, and that the information emphasises the difficulties and limitations encountered by those with CF. Such narratives may have implications both for individuals with CF and those around them, perhaps leading others to underestimate the abilities of those with CF or place unnecessary restrictions upon them.

⁵ A syndrome is defined as a series of connected symptoms with an unknown cause, while 'disease' is used to refer to illnesses with clear aetiology. In light of the ambiguity that remains regarding the classification of CF, the author will be careful to use the term 'illness' to refer to CF as this may infer either syndrome or disease. An exception to this may be in quoting the work of others, in which the terms employed by the authors will be used.

⁶ This is based on a 5 minute search of the internet using the Google search engine and the search term 'Cystic Fibrosis' and reading through the first 5 pages found.

Thus, it is evident that medical and societal narratives around CF may impact upon how the person understands their illness experiences (Smith & Sparkes, 2008). Moreover, they may inform how those around the person with CF perceive and interact with them, which may in turn impact on the individual's narrative and relationship with their illness (Blumer, 1969). This highlights the importance of the chosen research methodology, narrative inquiry (NI), which focuses both upon the immediate and wider context in which the narrative is constructed to develop understanding of the experience of living with CF.

1.2.4 Western Psychological Narratives around CF and the Problems of Adolescence

The CF Trust guidance on the management of CF (Cystic Fibrosis Trust, 2011), recognises that it is important to consider the psychological and societal implications of living with CF. Indeed, though the prospects of those with CF have improved over the last 20 years, significant physical disability still exists and CF continues to be a life-limiting illness. Moreover, increased life expectancy brings new challenges, particularly for young people, such as learning to manage their treatment (Badlan, 2006) and making important decisions about the future with the understanding that they face many challenges as an adult with a chronic, fatal illness (Stark, Mackner, Patton, & Acton, 2003). These challenges come at a time when the demands of having CF typically increase (Ernst, Johnson, & Stark, 2010). CF progresses from mild to moderate during childhood, becoming severe in adulthood (Maclusky & Levison, 1998). Thus, young people face many demands that might conflict with the developmental tasks of adolescence. For instance, time consuming treatment regimens, frequent appointments, and hospital admissions (e.g. owing to exacerbations of pulmonary infections) may impact upon peer relationships and academic achievement. Similarly, adolescent preferences may conflict with treatment, for example, the drive for slimness versus the need to consume high calorie foods (Besier & Goldbeck, 2011). Moreover, CF adolescents are typically shorter than their peers (Beker, Russek-Cohen, & Fink, 2001) and underdeveloped, with delayed onset of puberty (Boas, Fulton, Koehler, & Orenstein, 1998), which may set them apart from peers, leading to unfavourable social comparison and low self-esteem (Christian & D'Auria, 1997; Damon & Hart, 1992).

In light of the foregoing, the potentially deleterious impact CF may have upon psychological and psychosocial wellbeing in adolescence has been widely researched. Quantitative methods have predominantly been used to explore how young people with CF cope with their experiences during adolescence and whether they are more at risk than their healthy peers of adjustment difficulties and disruptions to psychological wellbeing. Interestingly, while some studies report that young

people with CF are at increased risk of anxiety (Modi, Driscoll, Montag-Leifling & Acton, 2011; Pfeffer, Pfeffer, & Hodson, 2003; Smith, Modi, Quittner & Wood, 2010), depression (Modi, et al., 2011; Quittner et al., 2008; Smith et al., 2010), and an impoverished quality of life (Goldbeck & Schmitz, 2001; Pfeffer et al., 2003), a similar number report no significant difference between the psychological wellbeing of young people with CF and their peers (Anderson, Flume, & Hardy, 2001; Besier & Goldbeck, 2011; Blair, Cull, & Freeman, 1994; Bregnballe, Thastum, & Schiøtz, 2007; Goldbeck & Schmitz, 2001; Havermans, Colpaert, & Dupont, 2008; Pfeffer et al., 2003; Szyndler, Towns, van Asperen, & McKay, 2005). Though sampling issues may account for some of this discrepancy (Goldbeck et al., 2010), the fact that evidence for and against the disruption of psychological wellbeing is well balanced suggests that while CF *may* have deleterious impact on psychological wellbeing during adolescence, this is not always the case.

Consequently, there has been growing interest in how young people manage the daunting task of balancing the functional limitations and demands of CF with the drive to attain important developmental goals (e.g., establish meaningful relationships, plan for the future etc.) (Badlan, 2006; Gjengedal, Rustoen, & Hanestad, 2003; Glasscoe & Quittner, 2008; Schwartz & Drotar, 2009) in order to limit the affective impact of CF and maintain a fulfilling life (Glasscoe & Quittner, 2008; Quittner et al., 2008; Schwartz & Drotar, 2009). How young people with CF manage these challenges may have important implications for the developing sense of self as during this period they begin to establish a sense of self, a process heavily influenced by interactions with others, and peers in particular (Erikson, 1968). For a young person with a chronic condition, interactions with others also heavily influence their illness perceptions (Eiser, 1990), which may have implications for acceptance⁷ and psychological wellbeing (Casier et al., 2011; Casier et al., 2008). Consequently, disruption to peer relationships in particular may have long-term implications for the young person's emotional wellbeing and sense of self (Eiser, 1993; Hartup, 1993; Ladd, 1990; LaGreca, 1990; Parker & Asher, 1987).

Despite the above, only a few studies have explored how CF influences peer relationships. Those that have, report that CF may have a detrimental effect on peer relationships owing to prolonged absence from school, as well as reduced opportunity to engage in social activities owing to symptoms of the illness (e.g. fatigue) and the demands of treatment (Cadman, Boyle, Szatmari, & Offord, 1987; Christian & D'Auria, 1997; Drotar, 1981; Wallander & Varni, 1992). This has also been associated with reduced self-esteem, though there remains some discrepancy as to whether this is

⁷ Defined as “*recognising the need to adapt to chronic illness while perceiving the ability to tolerate the unpredictable, uncontrollable nature of the disease and handle its averse consequences*” (Evers et al., 2001, p. 1027).

more pronounced in boys or girls (Landon, Rosenfield, Northcraft, & Lewiston, 1980; Sawyer et al., 1995). Nevertheless, these findings highlight a need for greater understanding in relation to how young people with CF manage their relationships and how through these experiences, they begin to establish a sense of who they are.

1.3 CF IN ADOLESCENCE AND THE EMERGING SENSE OF SELF

The preceding section focussed on the potential physical and psychological impact of CF. However, at the heart of understanding the experience of living with CF is the young person's story: their experiences of living with CF, their sense of self, and how the two are entwined. Accordingly, the ensuing section begins with a discussion of identity, and the reasons for adopting a social constructionist, postmodernist view of this, before moving on to consider how identity work may be influenced by chronic illness in general, and more specifically, in adolescents with CF.

1.3.1 Identity and Sense of Self(s): from Identity Status to Narrative Models of Identity

The definition of identity is dependent upon the epistemological position adopted. This study takes a social constructionist position, which would assume that there is no fixed self (Foucault, 1972). This contrasts with the modernist view that there is a fixed, identifiable, and examinable self (McCrea & Costa, 1999). Within the social constructionist framework, our sense of self, or selves, forms through our social interactions, the context in which they occur, and the broader current and historical narratives available (Elliott, 2005). Moreover, our concept of self is culturally defined and dependent on the ideals of our society, whether they are, for example, the individualistic ideas of Western culture or the collectivist ideas of Eastern societies. From this post-modernist position, the study of identity would be concerned with how the self is constructed in different contexts and how this is influenced by broader cultural and societal narratives.

As there are numerous ways in which identity may be defined, there are also a number of theories concerned with how it develops. The identity status paradigm, which originates from the work of Erikson (1968) and Marcia (Marcia, 1966; Marcia, 1993) dominates the literature on identity development appearing in over 500 articles, papers, and dissertations, and in practically every textbook of adolescent development (Waterman, 1999). This asserts that identity development occurs through a series of stages across the lifespan. The model nevertheless highlights adolescence as important as it is during this period that we begin to interact more with peers, and our capacity

for abstract thought increases (Inhelder & Piaget, 1958), allowing us to begin to test out and hone the fragile ideas of self that may have been created in childhood, (Kroger, Martinussen & Marcia, 2010).

The identity status paradigm has come to incorporate a variety of notions of identity status from the work of Marcia (1993) and Kroger (1992) which align themselves with Erikson's ego analytic perspective, to Berzonsky's (1990) constructivist, information-processing account of identity status, and more recently to those which draw on existential philosophy (Bilsker, 1992) and feminist perspectives (Archer, 1992). Nevertheless, these different conceptions of identity status are all underpinned by the belief that identity is a phenomenon which plays a significant role in development during adolescence and early adulthood (Waterman, 1999). Consequently, this has led to the belief within modern Western society that adolescence is a time for 'finding ourselves' and 'discovering who we are'.

Despite the usefulness and thus popularity of the identity status paradigm, it has been criticised for focusing on macro rather than micro-level processes (Pasupathi & Hoyt, 2009). While proponents of this model recognise the importance of intra-individual processes in the continued development of the self (Marcia, 1966; Marcia, 1993), this has made it difficult to determine the processes at work in progressing from one stage to the next, and arguably undermines the first person perspective, the importance the individual places on maintaining the same view of self over time, and how they reconcile their view of self with personal experiences (Atkins, 2004). In view of this, there has been increased interest in a narrative approach to identity as a means through which we may further our understanding of the micro-level processes involved in identity development. Within this approach, the concept of identity or sense of self is consistent with social constructionist or post-modernist definitions, and is therefore in keeping with the position held by this study. Thus, the remainder of this section will focus on narrative approaches to identity.

Whilst the identity status approach grew out of Erikson's (1968) notion of the management of psychosocial dilemmas, the narrative approach came from Erikson's ideas around lifespan development, as well as other work concerned with personality development (e.g., Adler, 1927; Murray, 1938). In this way, the narrative approach is not merely a means of exploring identity, with identity conceived of as an accumulation of thought and active decisions about particular areas of one's life (e.g. Dunbar & Grotevant, 2004). Rather, the narrative approach may be understood as a construct – *"it is not that the self is measured by assessing stories, but rather that the self is a story"* (McLean & Pratt, 2006, p.715). This is not to say that narratives are synonymous with narrative identity. Indeed, it is the narrator's interpretation and evaluation of their account of something that

has happened which reflects and constructs narrative identity (Pasupathi & Hoyt, 2009). Moreover, it is these features of narrative construction that are thought to be related to the development of identity and a sense of self in childhood (e.g., Bird & Reese, 2006; Bohanek, Marin, & Fivush, 2006; Fivush, 1991; Fivush, Bohanek, Robertson, & Duke, 2004; Harley & Reese, 1999; Howe, Courage, & Peterson, 1994), adolescence and early adulthood (McLean & Pratt, 2006; Sutin & Robins, 2005), and are linked to psychological well-being throughout adult life (King & Patterson, 2000; McAdams, Reynolds, Lewis, Patten, & Bowman, 2001; Pals, 2006a, 2006b). Consequently, narrative approaches to identity development are concerned with how individuals make sense of their experiences and thus further their sense of self and identity (McAdams, 1996).

The narrative approach is arguably well suited to the study of identity as it is consistent with the assumption that the need to tell stories is a trait shared by all humans (Bruner, 1990). Proponents of this view argue that the construction of narratives about one's life allows the person to develop a sense of continuity over time as the past and future selves are represented and interpreted by the present self, and is therefore, paramount to the development of a sense of self (McLean, Pasupathi, & Pals, 2007; Pasupathi, 2001; Thorne, 2000). In making this case, these authors highlight the importance of the context of the narrative, suggesting that narrative identity develops via the micro-process of constructing specific narratives in specific situations. Furthermore, narrative construction and thus narrative identity is deemed to be influenced by the broader context in which it occurs as experiences and the self are storied into narratives that are valued by the person's culture and society (Bruner, 1990). Thus, narratives allow exploration of uniqueness, and of how the individual uses cultural scripts and schemas to organise their personal narrative (Pasupathi & Hoyt, 2009).

While narrative identity differs from the notion of identity put forward by proponents of the identity status approach, research has explored whether there may be a link between the meaning making processes taking place in the construction of narrative identity and the shifts between identity statuses (Mackey, Arnold, & Pratt, 2001; McLean & Pratt, 2006). While these studies found a modest overlap between these approaches, they also reported significant disparity, suggesting that each approach offers a distinctive lens on identity, emphasising either objectivity or subjectivity (McLean & Pratt, 2006). Specifically, through a longitudinal study of the turning point narratives of emerging adults, McLean and Pratt (2006) found that in the narrative approach, topics of identity are chosen by participants, rather than imposed as per the identity status approach, which might mean that stories presenting particular identity statuses may not emerge in one's narrative if they are not considered personally meaningful.

The findings of McLean and Pratt (2006) are consistent with Mishler's (1999) view that the identity status model is an artefact of a variable-centred research approach designed to permit generalisations across groups and in doing so, fails to acknowledge the discontinuities, subjectivities, and multiple pathways that more accurately reflect identity across the life course⁸. This may have implications for identity research, where the focus is on the development of identity in the face of dominant ideas about the topics and roles that may be important for a particular group of people. As noted by Kelly and Millward (2004), one such area may be the study of identity in people with chronic illness. Indeed, they highlight the importance of introducing subjectivity to accounts of illness identity to challenge the dominant discourses that surround illness, such as the sick role paradigm established by Parsons (1951)⁹, thus promoting a sense of agency and recognising the importance of interaction for the developing sense of self. For this reason, illness narratives have enjoyed increasing popularity as a means to explore the development of identity in people with chronic illness. In view of the focus of this study, the ensuing sections will consider how people use narratives to make sense of their illness experiences, what may be learned through the study of illness narratives, and how these ideas may apply in the context of young people with CF.

1.3.2 The impact of chronic illness on self narratives

Many researchers have used a narrative approach to explore the unique and often complex responses of individuals learning to live with chronic illness (e.g. Koch, Kralik, & Sonnack, 1999; Kralik et al., 2000, 2001, 2004; Williams, 1984). Underlying this, is the assumption that people make sense of their experiences through the stories they tell, and that through consideration of the content, context, and structure of these stories, we may gain an insight into the subjective experience of living with chronic illness. Thus, the narrative approach allows the person's illness experiences to be situated within a wider psychosocial context, and encourages the reader to connect with the person's emotional experience (Bleakley, 2005).

The concept of biographical disruption (Bury, 1982) has proven particularly influential in the application of a narrative approach to the study of chronic illness. This is the idea that individuals with chronic illness undergo a process of narrative reconstruction, in an attempt "to establish points of reference between body, self, and society and to reconstruct a sense of order from the

⁸ Nevertheless it is important to note that the identity statuses model continues to be useful in allowing researchers to explore broad dimensions of identity development across many experiences in our lives (McLean & Pratt, 2006).

⁹ While Kelly and Millward (2004) highlight the value of the Parsonian system in recognising the social as well as the biomedical aspects of illness, they acknowledge that placing someone in a role, removes agency.

fragmentation produced by chronic illness”, (G.Williams, 1984, pp 188). In short, the re-establishment of self-identity is seen as crucial in adjusting to chronic illness. Though useful, this idea takes the epistemological stance that ‘the self’ is pre-existing and is reflected in the narrative. This is inconsistent with the social constructionist perspective, within which the self is seen as constructed at least in part through the telling of the narrative (Riessman, 2008). The latter position is adopted in the work of Charmaz (1983, 1995). She posits that the self (or selves) is developed and maintained through social relations and shaped by cultural meanings, and that we attempt to construct and perform a preferred narrative which presents a consistent image of the self over time (Charmaz, 1983). From this position, Charmaz (1983) argues that the illness onset threatens the consistent and arguably valued sense of self that has developed and reduces the opportunity for social interactions that might help the person to develop a new, equally valued sense of self. Moreover, she notes that the interactions the person experiences may be influenced by the person’s relationship with their illness and body, such that those who perceive themselves or their lives as fragile might be more sensitive to discreditation or negative self-reflection from others, at a time when their sense of self is more tied up in the other (Charmaz, 1983)¹⁰.

While influential, Charmaz’s (1983) idea of ‘loss of self’ stems from research with adult onset illnesses where the ‘normal’ healthy state shifts to one of illness. This is also true of the concept of biographical disruption (S. Williams, 2000). Thus do these ideas reflect the experiences of children where the illness is part of the forming identity, and where continuity is the guiding principle (S.Williams, 2000), or rather where the onset of identity development might disrupt the sense of normality and biography that had previously been established with regard to the illness during earlier childhood (Kegan, 1982). There remains little research looking at how young people make sense of their experiences of chronic illness. Research in this area typically seeks to understand the impact of chronic illness on areas including but not confined to relationships, psychosocial adjustment, and treatment management (e.g. La Greca, 1990; Olsson et al., 2003; Schuman & La Greca, 1999; Woodgate, 1998). To date, a narrative approach has been used in only two studies, to explore children’s experiences of childhood cancer (Woodgate, 2005), and juvenile arthritis (Guell, 2007), one of which combines the children’s narratives with those of other family members (Woodgate, 2005). Consequently there remain few examples of children’s narratives in the literature (DasGupta, 2007). Moreover, in both the studies mentioned above, there is a sense that the illness brings about a change from a ‘normal’ healthy state. Thus while they highlight the benefits of using this approach to explore the experiences of young people with chronic illness (Woodgate, 1998),

¹⁰ This is perhaps reflected in the quantitative literature, with findings demonstrating how illness perceptions are closely linked to psychological wellbeing and to a greater extent than ‘actual’ illness severity (Hagger & Orbell, 2003; Kaptein et al., 2003).

there remains a need to consider the experiences of those for whom illness is a part of the child's developing identity, as may arguably be the case for young people with CF.

1.3.3 CF and sense of self in adolescence

Earlier discussion highlights how research on CF has been primarily concerned with differences between those with CF and their healthy peers. While these studies provide a means to classify experience providing categories or possible trajectories that may be beneficial to medical treatment and understanding, they lose sight of the individual, and the idiosyncrasies of each person's experience of living with CF. While there are a handful of studies that provide insight into how young people with CF begin to make sense of their illness experiences (Badlan, 2006; Christian & D'Auria, 1997; D'Auria, Christian, Henderson & Haynes, 2000; Demetriades, & Jacobs, 2006; Jessup & Parkinson, 2010; Williams et al., 2009), consistent with the arguments put forward above, these are generally concerned with issues of relationships, psychosocial adjustment and treatment management. However they highlight some of the issues that young people with CF may be concerned with, which may influence the meaning making process.

A review of the qualitative studies of CF in adolescence suggest that maintaining normalcy and reducing feelings of difference may be important features of the young person's illness experience. Early research in this area (Christian & D'Auria, 1997; D'Auria et al., 2000), looking at adolescent conceptualizations of their chronic illness, found that feeling different from peers significantly impacted upon peer relationships, particularly in early adolescence. Applying a grounded theory approach, the authors found that reducing a sense of difference through keeping secrets, and hiding visible differences from peers was important in early adolescence (Christian & D'Auria, 1997). However, these behaviours, along with increased ill health and hospital admissions were said to promote feelings of 'being out of the loop' and 'losing ground' with peers in middle adolescence. Thus their research highlighted the potential difficulties that young people with CF faced as they attempted to form relationships with healthy peers. Interestingly, their research also showed how with increased hospital admission, came increased opportunity for contact with others with CF, allowing the young people participating in their research to find a new 'baseline' and new 'company of friends' though also providing insight into the 'never ending battle of CF' (D'Auria et al., 2000). Owing to the reduced opportunity for young people with CF to meet others with this illness in light of changes to healthcare practices imposed to reduce the likelihood of illness (e.g. segregated clinics, Cystic Fibrosis Trust, 2004), the extent to which this finding may reflect the experiences of young

people within contemporary society is questionable. Nevertheless, with the popularity of social media sites making it ever easier to contact others, it is worth holding this finding in mind.

The findings of D'Auria and colleagues demonstrate how the desire young people with CF have to be perceived as 'normal' may interfere with peer relationships. This was compounded by their visible difference from peers, a factor which may be less significant in light of improvements in treatment and the subsequent health of young people since the time this study was conducted. Nevertheless, Demetriades and Jacobs (2006) more recently reported similar results in a sample of 12-16-year olds with CF. The idea of difference again emerged in the themes of feeling 'alone in a crowd' and 'being the only one', which the young people attempted to manage by controlling the visible aspects of CF. Interestingly, they also found females were more likely than males to use relationships as a means of support, suggesting that there may be gender differences in the role played by peers in helping the young person make sense of their illness experiences.

Building on the above, the findings of Badlan (2006) show how the issue of difference may be more complicated. Through her investigation of how the experiences of young people living with CF influenced adherence to treatment, Badlan found that while the young people interviewed talked about being 'normal', there was also a sense that they were an 'imposter' in the normal world. Badlan argued that within her sample, difficulty determining normalcy seemed to reflect difficulty determining whether they were in fact healthy (and therefore normal) or unhealthy (abnormal). Indeed, as the lives of young people with CF may contain many similarities to those of their peers but with some clear differences (e.g. treatment), they may be left with the dilemma about whether or not they are 'unhealthy' (Pinder 1996, Lowton & Gabe 2003). Badlan (2006) discussed these findings in relation to the implications they may have for treatment adherence, suggesting that as treatment may be a reminder to the young person of being 'unhealthy' and therefore different from peers, this may be a factor in reduced treatment adherence. However, as it was beyond the remit of their study, it remained to be seen how this more complex relationship with normalcy might influence peer relationships and thus the developing sense of self.

A more recent study by Williams and colleagues (Williams et al., 2009) builds on the findings of Badlan (2006). Using a grounded theory approach to explore the accounts of a sample of 7-17 year olds with CF, they found that the idea of normalcy was used in different ways at different times, with distinctions emerging between personal and societal definitions of normalcy and in terms of who the young people saw as the audience for the normalcy (i.e. self or others). Interestingly, one way in which normality was construed was that of the experiences of illness being normal-to-self. As such, it is unlikely that the notion of disruption or loss of self as talked about by Bury (1982) and Charmaz

(1983) respectively, might apply to the illness experiences of young people who are likely to view illness through a 'normalcy' lens (Robinson, 1993). These findings suggest that the young person may be able to hold different and sometimes conflicting views of normality and that these may be played out at different times and for the benefit of different people. Williams and colleagues (2009) argue that in spite of improvements to healthcare, these findings indicate that young people with CF continue to feel that society is not accepting of their differences and that they need to modify their behaviour to meet the expectations of others.

In view of the findings to date, it would seem that young peoples' perceptions of what is normal for both self and others influences their way of relating to self and others in their experiences of CF. However further research is needed to better understand the challenges faced by young people as they hold onto these conflicting notions of normality, and the implications this may have for the emerging sense of self. The handful of qualitative studies conducted thus far highlight how this approach may enable us to better understand the subjective and different experiences of CF apparent both within and between individuals. Indeed, illness narratives, while at risk of portraying a romanticised view of illness (Frank, 1995) provide valuable insights into individuals' illness experience and demonstrate how these experiences go beyond those recognised by the medical model. Nevertheless, considered in isolation, what we may learn may be limited. Without consideration of the local and broad contextual factors influencing narrative construction we may lose sight of the reasons why the person's experience has been storied in a particular way within a particular context (Riessman, 2008). Such information may be crucial in understanding the narratives of young people with CF: how they make sense of their illness experiences within contemporary Western society, and the identity work taking place through the narrative's performance. This critique may be levelled at all the studies discussed here, and highlights a need for further research to consider not only what is told, but how it is told in relation to local and wider contextual factors. Thus, a narrative exploration of young people's stories of living with CF might offer valuable insights into their experiences, offering an opportunity to develop a more holistic picture which might inform clinical practice.

1.4 CLINICAL RELEVANCE

People's subjective experience is arguably more valuable to clinical understanding than the description of the likely experiences of a given population obtained through quantitative research (Popay & Williams, 1998; Williams & Popay, 1994). In contrast to more traditional methods of

inquiry, the narrative approach to illness offers insight into the experiences of living with an illness at a local and societal level. In an illness such as CF, where the presentation of the illness varies significantly from person to person, and where improvements in care mean that people diagnosed now will likely experience a very different illness trajectory than might have previously been the case, a narrative exploration of the experiences of young people with CF may provide important information that may be used to further clinical understanding and inform improvements to practice. This is consistent with recent drives within the National Health Service (NHS) which recognise the importance of listening to the stories of those with chronic conditions and working with 'expert patients' to develop greater understanding of how best to support the individual to manage the effects of their condition (Department of Health, 2003; see also Donaldson, 2003).

1.5 SUMMARY AND AIMS OF THE STUDY

CF is the most common genetic, life threatening disorder in the UK (Cystic Fibrosis Trust, 2010). The illness trajectory means that adolescence may be a challenging time as young people balance the increasing demands of CF with the drive to attain important developmental goals (Badlan, 2006; Gjengedal et al., 2003; Glasscoe & Quittner, 2008; Schwartz & Drotar, 2009). Moreover, research suggests that during this period young people become aware of their difference from peers, which may have implications for peer relationships and the young person's developing sense of self (Christian & D'Auria, 1997; D'Auria et al., 2000; Williams et al., 2009). To date, research in this area has been largely quantitative in nature. Moreover, studies that have employed a qualitative approach may be limited as they overlook the contextual factors that may influence how the young person makes sense of their experience. Although, they highlight the insights that may be gained through qualitative research, a narrative approach may allow us to consider contextual factors providing valuable additional information.

Narrative construction may provide those with chronic illness an opportunity to seek and regain a sense of autonomy and agency (Frank, 1995) and offer researchers valuable insights into how individuals make sense of their illness and integrate their experiences into their identity. Consequently, this study aims to better understand what it is like to be a young person with CF, through hearing their narratives and exploring their construction in relation to local and broader contextual factors. Through this, it is hoped that we may gain further insight into how young people make sense of their experiences, which might enable health professionals to provide better understanding and support.

The main research question is: how do young people with CF make sense of their illness in narrative?

This will be explored through the following, specific research questions:

- (i) How do these narratives describe and account for their relationship with CF over time?
- (ii) What aspects of the self are expressed in these narratives?
- (iii) How do the young people position themselves relative to themselves, others, and the broader societal narratives available to them?

2.1 OVERVIEW

The chapter opens with details of the methodology and rationale for its use. This includes the epistemological position taken in this study, and justification for the use of a qualitative approach, specifically, narrative inquiry. Following this, the research design is presented, providing a detailed explanation of the interview schedule and photo elicitation methods used to obtain the stories, and the process of data analysis, to ensure that the reader is in a position to evaluate the suitability of the design and chosen analysis. Finally, to afford the reader the opportunity to assess the credibility of the study, the chapter closes with discussion of the steps taken to ensure trustworthiness, rigour, and credibility.

2.2 METHODOLOGY

2.2.1 Qualitative Research

Since the second half of the twentieth century, researchers have questioned how much we can learn about the social world through traditional positivist methods of scientific enquiry (Riessman, 2008). In quantifying human experience such methods overlook the diverse array of experiences and contexts that exist (Krahn & Putman, 2003). By contrast, qualitative designs allow researchers to gain a rich, ideographic perspective by collecting individual data, through which they can explore meanings and experience (Chamberlain, Stephens & Lyons, 1997).

Research into adolescents' experiences of CF has typically employed a quantitative approach. While such research is necessary to highlight the broad issues facing this group, the few qualitative studies that have been conducted illustrate how a richer understanding of the experiences of young people with CF may inform clinical practice. Consequently, a qualitative approach was selected to further explore this currently under-researched area (Liamputtong & Ezzy, 2005). To determine the specific method of qualitative enquiry to be used, it was necessary to consider the research questions and underlying epistemological position of the study (Pearce, 2009).

2.2.2 Epistemological Position

Informed by the belief that previous research is limited in how well it captures the narratives of young people with CF, this study took an exploratory stance, aiming to hear the diverse range of experiences of young people living with CF. A constructionist position was adopted, attributing value to the language used by individuals to construct their accounts of their experiences (Riessman, 1987) as their knowledge is conveyed in linguistic form (Kvale, 2007). This posits that while people construct their own meanings (essentially a constructivist position), their narratives are shaped by the language available to them, and the meaning ascribed to it by society. Therefore, just as the language used is “already someone else’s” (Halasek, 1999, p.177), so too are the stories told. Within this approach, the researcher is not only interested in the narratives constructed but how the person draws on and/or resists cultural narratives in storying their experiences.

From a constructionist perspective, it is recognised that the accounts of the young people interviewed for the purpose of this study cannot be considered ‘absolute truth’. Rather, the narratives are co-produced by the interviewer and interviewee (Fontana & Prokos, 2007; Lyons & Chipperfield, 2000). This does not mean that the interviewee and interviewer necessarily share the same perspective, but that the process of storytelling is influenced by their interactions, social locations, and the personal and societal values which inform the construction and understanding of the narrative (Capps & Ochs, 1995; Witten, 1993). Similarly the narrative produced may be influenced by the interviewee’s perception of the researcher (Goodley, 1996). Subsequently, the stories told may be considered ‘data as topic’ as the content of the narrative reflects the co-constructed reality in which the story is formed (Seale, 1998). The narratives may be understood as temporally specific: differing significantly from stories told to different audiences at different times as the individual’s construction of meaning shifts relative to new relationships and experiences (Pearce, 2009).

2.2.3 Justification for the use of Narrative Inquiry (NI)

The qualitative framework employed within this study was based on the principles of NI (Bamberg, 2004, 2007, 2011; Riessman, 1993; Wells, 2011). This offers guidance to the focus of inquiry, the approach to data collection, and the nature of analytic focus.

NI refers to a family of methods for interpreting storied language, which have developed across a diverse range of disciplines including history, anthropology, sociolinguistics, and the social sciences (Riessman, 2008). Owing to its multidisciplinary origins, NI encompasses a range of approaches

which have their roots in different and often conflicting theoretical positions, disciplinary frameworks and methodological approaches (Squire, Andrews, & Tamboukou, 2008). Nevertheless, a number of core assumptions underlie many forms of NI used today. These provide a useful framework within which to explore the questions posed in this study.

Firstly, a primary assumption underlying NI is that narratives are “sequential and meaningful, relate to human experience, and display transformation or change” (Squire, 2008, p.42). They are a means by which individuals understand themselves and the world and make sense of disruptions to normality (Bruner, 1990; Squire, 2008). Within the context of this study, NI therefore allows exploration of how young people make sense of their experiences of CF.

Secondly, unlike other qualitative approaches which are predominantly concerned with the analysis of content (e.g. Interpretive Phenomenological Analysis, Thematic Analysis), NI also considers *how* and *why* incidents are storied (Bamberg, 2004, 2007, 2011; Riessman, 2008): how the speaker constructs their story, to whom the story is being told, and the reason for telling it (Wells, 2011). This lends itself to consideration of not only the content of the stories told by young people with CF, which may allow exploration of how they make sense of their illness experiences, but also permits consideration of the dialogic aspects of the narrative and what aspects of the self may be being expressed within the co-construction of their stories.

Thirdly, implicit in the assumption that narratives are co-constructed is the belief that narratives are shaped by the local and broader context in which they occur (Benwell & Stokoe, 2006). Concerning the local context firstly, NI makes explicit the role of the interviewer and the interview environment in narrative construction and performance. This allows exploration of the dynamics of the relationship, the role of the researcher, and the local environment through consideration of questions such as: *how does the interviewee perceive the researcher? How might the location and other environmental factors shape the narrative? What is the individual trying to accomplish through telling their story in this way?*

Regarding the wider context, NI takes into account the influence of family, occupational, and wider cultural narratives that might influence how the speaker constructs and performs their narrative. Consideration of the ‘narrative environment’ (Gubrium & Holstein, 2009) permits the researcher to explore how the interviewee positions themselves relative to dominant cultural narratives as well as how their performance may be shaped by wider audiences (e.g. family, peers, hospital environment, society etc.). Within this study, this may allow insight into how the young person makes sense of

their illness experience relative to dominant narratives (e.g. of illness and adolescence) and how their performance is indicative of how they wish to be perceived by others.

Fourthly, narratives are thought to closely reflect people's sense-making strategies (Bamberg, in press; Polkinghorne, 1988) and are thus a performance of *who we are* and the stories which we live by (McAdams, 1993; Randall, 1995), representing "the participants' subjectivities and from there reflecting back on their identities" (Bamberg, 2008, p. 378; though for a critique of this position see Atkinson & Delamont, 2006). Consequently, narratives hold a privileged position in understanding the identity work carried out as individuals attempt to reconcile their experiences into a coherent story of the self (Bamberg, 2011). As noted in section 1.3.1, this approach does not view identity as something a person has, but as something that is constructed and negotiated in our social encounters (Bamberg, 2010). Nevertheless, the identity work taking place in each encounter does not occur from scratch, but rather each telling is a "situated version of previous telling, which is constructed as part of a speaker's identity work" (Taylor & Littleton, 2006, p.25).

While narratives range from brief storied responses to single questions, to biographical accounts of entire lives (Riessman, 2008), the latter has been the subject of the majority of narrative inquiries into identity work (Bamberg, 2011). Drawing on the work of Polkinghorne (1988), Bruner (1991), and Sarbin (1986, 2003), McAdams and colleagues (1985, 2006), put forward the life-story model. This proposes that "in the emerging adult years....people begin to put their lives together into self-defining stories" (McAdams & Janis, 2004, p. 161) which may be reflected in biographical accounts. However, this approach requires a level of skill and practice in the art of reflection and narrative formation that may not be afforded by those who are 'not-yet-adult' (Bamberg, 2008). It may be anticipated that the young people taking part in this study are unlikely to produce extended, coherent accounts of their lives. Thus, it may be helpful to draw on an alternative approach to narrative which privileges 'small stories' that develop in day-to-day conversations (Bamberg, 1997, 2003; 2007; 2008; Bamberg & Georgakopoulou, 2008; Georgakopoulou, 2004, 2005a, 2005b, 2006, 2007a, 2007b). This approach views conversation as opportunities to practice and test out identities, and all conversations are seen as equally important in this process, whether they take place at the dinner table or in an interview setting (Bamberg, DeFina, & Shiffrin, 2011). This approach therefore lends itself to the exploration of identity and the construction of self in the young people taking part in this study.

2.2.4 The choice of Narrative Analysis (NA) over other Qualitative Approaches

For the reasons discussed, it was felt that the narrative approach lent itself to consideration of the content of the stories obtained, how they were performed, and how they were shaped by contextual factors, allowing insight into the emerging sense of self. This focus on the performative aspects of the stories told distinguishes narrative from phenomenological approaches such as Interpretive Phenomenological Analysis and Thematic Analysis which analyse experiences in isolation and have been criticised for providing an uncritical understanding of the phenomenon under investigation (Yardley, 1997). While several studies mentioned in the literature review employed a Grounded Theory approach, this was incongruous with the epistemological position of this study and was thus discounted. Furthermore, much may be gained from exploring the dominant narratives and discourses which the young people in this study are drawing on to construct their narratives. As Discourse Analysis focuses on the use of language rather than the wider context on which people draw (Burr, 2003), this was ruled out.

2.3 DESIGN

2.3.1 Sampling Strategy

Participants were selected using purposive sampling methods (Patton, 1990). In contrast to quantitative research that employs random sampling methods to ensure a representative sample is obtained from which findings may be generalised to the target population, purposive sampling methods are more typically employed in qualitative research to obtain a sample which captures the range and diversity present within the target population. Within this framework, participants are selected based on certain characteristics which match the defining features of the target population.

Owing to the large quantity of verbal data obtained using qualitative methods (LoBiondo-Wood & Haber, 2002) it is appropriate to use a small number of participants (Silverman, 1997). I had initially planned to obtain a sample of 8-12 participants (males and females). However, owing to time constraints and a desire to consider the rich data obtained, this was reduced to 5-6 participants. This is consistent with Wells (2011) who argues that in narrative studies involving complex and detailed analyses, a sample of 5 is sufficient and allows for more in-depth exploration of the data.

As this study sought to explore the experiences of adolescents with CF, the following criteria were used to structure the process of participant selection and recruitment:

Aged 12-16 years: Consistent with other research in the area of chronic illness in adolescence (Christian & D’Auria, 1997), the study initially aimed to employ participants aged 12-18 years. However, on further consideration the upper limit was reduced to 16 years of age, to ensure that all participants shared certain experiences (i.e. being in Secondary education), creating greater homogeneity within the sample.

Fluent English Speaking: This type of qualitative research relies heavily on language use, both in the production of narratives (during interviews) and in the analysis where the emphasis is not only on the content of what is said but the subtleties of language use, metaphor etc. As the richness and meaning of language can be lost when using translators¹¹ only English-speaking participants were included in this study¹².

Not Under Acute Admission, Child Protection Proceedings, or Having Received a Lung Transplant: To maintain homogeneity among the experiences of the young people included in the study, individuals were excluded who had undergone lung transplant surgery, were under acute hospital admission or where child protection proceedings were under way. This was because the experiences of these individuals were likely to be qualitatively different from those of young people with CF more generally¹³. Moreover, it may be unethical to involve young people who were acutely unwell or where there were concerns as to the child’s safety.

2.3.2 Recruitment Process

Participants were recruited through a specialist CF clinic at the Addenbrooke’s Hospital in Cambridge. This was arranged via liaison with the Consultant Paediatrician, Dr Richard Iles, and Clinical Psychologist Dr Ruth Easby who were keen to facilitate the study. To recruit via this NHS site, ethical approval from the National Research Ethics Committee (NRES) and the local Research and Development (R&D) office was obtained. Details of this process can be found in section 2.4.

¹¹ The researcher was fluent only in English

¹² This meant that the voices of non-English speaking adolescents were excluded which is not ideal from either a research or ethical perspective. However, discussion with the consultant paediatrician based at the CF clinic from which participants were recruited did not identify any young people being seen whose language would make them ineligible for the study. Thus this inclusion criterion is unlikely to have resulted in significant exclusions of young people.

¹³ For example, research on lung transplants in CF highlights that undergoing the surgery and adjusting to life following surgery may bring specific challenges to the development of identity and peer relationships that are qualitatively different to those more commonly faced by young people with CF (Christian, D’Auria, & Moore, 1999).

Potential participants were identified by the clinical paediatric team working with the young person with CF according to the criteria outlined above. Those deemed eligible for the study were contacted by the NHS research site to prevent the need for access to clinical documents and personal data. Potential participants were sent a letter of invitation and information sheet containing the researcher's contact details (see appendices D and E) and advised that they could contact them by email/text/post should they wish to participate or find out more about the study. The initials of those informed of the study were then passed onto the researcher so that she was aware of when information pertaining to the study had been passed on.

Potential participants were given 10 days to contact the researcher. If they did not contact the researcher in this time the consultant was informed and asked to contact the young person and their parent to remind them about the study. They were told that if they did not contact the researcher within a week of this reminder, it would be assumed that they did not wish to participate and they would not be contacted about the study again.

Where the young person (and their parents in the case of those under 16years) wished to participate, plans were made to meet at a location convenient to them, to discuss the study in more detail and obtain written informed consent. Clinical staff and the young person's General Practitioner were then informed that the young person (and parents where applicable) had agreed to participate in the research¹⁴.

2.3.3 Selected Participants

Of the 43 young people under the sole care of the Addenbrooke's CF clinic, 24 met the inclusion criteria. Of these, those who registered an interest in the study first were included in the study. Those who contacted the researcher after the required number of participants was obtained were thanked for their interest and informed that recruitment was complete.

Basic demographic information was obtained during the first meeting with those participating in the study, to provide context to the sample (Elliott et al., 1999). Participants were advised that they did not have to answer these questions, and that approximations were acceptable if they were unsure

¹⁴ From this point forward, clinical staff had no further involvement in the study. This was to ensure that participants would not feel unfairly influenced or pressured into taking part/continuing their involvement should they wish to withdraw at any time. This also complied with the data protection act, ensuring confidentiality.

of the answer (e.g. number of hospital admissions in the last year). Details obtained are presented in Table 1.

Table 1. Demographic information of participants

Pseudonym	Age	School Year	Ethnicity*	Religious Beliefs*	Approximate number of hospital admissions in the last year
Amy	16	Year 11	White British	None	1
Miranda	12	Year 7	White British	None	None
Claudia	13	Year 8	White Mixed heritage Italian and English	Catholic	1
Rob	15	Year 11	White British	None	None
Sara	14	Year 9	White Mixed Heritage European	None	2
Daniel	12	Year 8	White British	Christian	None

* Self-categorisation

2.4 ETHICAL CONSIDERATIONS

2.4.1 The Process of Ethical Approval

Ethical approval for the study was sought from the National Research Ethics Service (NRES) which oversees research conducted within NHS settings (local approval was obtained from the R&D Department for Cambridge University Hospitals Trust). To obtain NRES approval, several amendments to the protocol were requested by the NRES review committee. The most notable concerned the use of photograph elicitation (see section 2.5.3). It was initially proposed that participants would be allowed to photograph anything that they felt would help someone to understand ‘what it was like to be a young person with CF’. However, the NRES committee were concerned that allowing the inclusion of photographs of people may be problematic owing to issues of consent. Therefore, the final protocol stated that photographs of people could not be included¹⁵.

¹⁵ In spite of this being clearly stated in the guidance to participants, three out of the six participants presented me with photos containing family members and friends. When this was pointed out to them prior to the interview all indicated that the people in the photos were an important part of their lives and it would be

However, as literature highlights the importance of social interaction in the construction of self (e.g. Erikson, 1968; Marcia, 1966), participants were informed that they could represent social interactions in other ways (i.e. photographs of places they might visit with significant others) to ensure that they felt able to talk about these aspects of their lives.

As an aside, the process of going through NRES had a significant impact on my relationship with this study. I felt heavily critiqued by some members of the review board who expressed concerns about employing young people in this research, leading me to doubt whether I should continue. However reflecting on this, I wondered how typical my experiences might be of those who aim to capture the voice of young people and whether this might explain a lack of research in this area thus far. Consequently, I felt compelled to continue with the study and found new enthusiasm. Thus, in case of an unfavourable ethical decision from NRES¹⁶ I looked for other possible avenues through which I might obtain participants. Subsequently, I applied for ethical approval from the University of Hertfordshire to recruit participants from the CF Trust Facebook page¹⁷.

Though the NRES application concerned all aspects of the study, key ethical concerns are detailed below.

2.4.2 Explaining the Research

Potential participants (and parents/carers of those under 16 years) were provided with a detailed information sheet explaining the activities of the research, the aims of the study, the requirements from participants, and their rights as participants (see appendices E-G). Furthermore, the healthcare professionals working with potential participants were provided with study information so that potential participants could talk to them about the study. Potential participants were also advised that they could contact the researcher via email or telephone if they had any questions about the study. The methods employed to inform participants of the role of the research and researcher satisfied ethical considerations and enhanced the transparency of the study.

difficult to talk about who they are without referencing them. Thus, it was agreed that they could be used to facilitate the interview but that the researcher would not retain copies of the photos, instead making a brief note about who was included to assist in the analysis.

¹⁶ A significant number of changes were required for NRES. Thus I was unsure whether it would be possible to make the required changes needed for a favourable ethical opinion to be obtained in time for the project to go ahead using participants recruited via NHS settings.

¹⁷ As participants were not subsequently recruited via this route, details of the intended protocol are not included here, but can be found in appendix C.

2.4.3 Confidentiality & Consent

The detailed information provided to individuals allowed them to make an informed decision about whether they wished to participate in the study. Those who wished to participate were asked to sign a consent form in the presence of a witness¹⁸ (appendices H-J). Those under 16years of age were asked to sign an assent form to state that they agreed to participate, while consent was sought from a parent/carer, in accordance with British Psychological Society guidelines (BPS; 2005). Participants (and the parents/carers of those under 16years) were informed that anonymity and confidentiality would be maintained by removing identifying information, using pseudonyms in transcripts, anonymising quotes, and storing all data in locked filing cabinets accessible only to the researcher. This process was in accordance with ethical considerations and served to increase the awareness of safety boundaries for the participants.

2.4.4 Avoidance of Harm and Debrief

Having the opportunity to reflect on the experience of living with chronic illness may be beneficial to psychological wellbeing (Rich, Lamola, Gordon, & Chalfen, 2000). Nevertheless, the interview could raise potentially uncomfortable issues of which the participant may not have been explicitly aware. Consequently, throughout the interview process the researcher maintained sensitivity to signs of distress from participants. Prior to the interview, participants were informed of the potential risks of participating and were advised that should they experience any distress the interview would be suspended or terminated. Time would then be given to talk through these concerns. All participants were advised that they could have a family member/friend close by (but not in the interview room) for support should they feel they would benefit from this. A plan to offer participants (and parents/carers) the opportunity to speak to a Clinical Psychologist was in place were this felt to be necessary. On completion of each interview, participants were given an opportunity to discuss questions or concerns, and to feedback on the interview process. They were also provided with details of an independent body that may provide support or field complaints should they feel this was necessary.

¹⁸ This was in all cases a parent.

2.5 PROCEDURE

2.5.1 Collecting Participants' Stories of their Experiences

While narratives may be obtained via a number of mediums, the qualitative research interview is the most widely used (Riessman, 2008) and was the method chosen for this study. This approach to NI has received some criticism as it is argued that the individual may not have chosen to talk about the research topic, or spoken about it in the way they did without the guidance of the researcher (Potter & Hepburn, 2005). Nevertheless, the interview may be viewed as a widely recognised and natural form of interaction within Western culture (Atkinson & Silverman, 1997), with its own conventions which are known to both members of the interaction (Shakespeare, 1998). Furthermore, if this situated talk is a new version of what has been previously said, it is likely that the interview will provide an appropriate context to view the ongoing identity work of the individual (Bamberg, 2008 Bamberg & Georgakopoulou, 2008; Taylor & Littleton, 2005) which is the interest of this investigation, and will attract participants whose life circumstances make the research topic interesting to them (Taylor, 2001).

Nevertheless, holding in mind the criticism above, it was necessary to ensure that participants were given the space to tell their stories within the context of the research interview. Consequently, the interview structure and process required careful consideration. Details of the structure and process of the interview are provided below, along with exploration of the reasons for these approaches.

2.5.2 The Interview Process: Obtaining Participants' Stories

To ensure that the environment in which the interview took place was conducive to narrative production (MacDonald & Greggans, 2008) participants were interviewed in a location of their choosing. For most, this meant that interviews took place in their own homes. However one participant was interviewed on a hospital ward during a routine admission. For all interviews, a member of the research team was made aware of when and where the interview would take place, and the researcher arranged to contact the research team member on completion of the interview and/or if any problems arose. It was agreed that should the research team member not hear from the researcher after 2 hours of the scheduled interview start time, they would contact the

researcher to ensure there were no problems. This was in accordance with the lone worker policy issued by the University of Hertfordshire (CRIPACC).

Prior to the interviews, participants were informed that interviews would be carried out on a one-to-one basis, though they could have someone nearby (e.g. in another part of the house) if this would help them to feel more comfortable.

At the beginning of each meeting, the young person information sheet was reviewed with the participant and their parent and they had the opportunity to raise questions or concerns. They were reminded that the interview would last approximately an hour (though may be paused for breaks) and that the interview would be audio recorded.

On completion of the interview, the audio recorder was turned off and the young person was given the opportunity to reflect on how it had felt to participate in the research. They were then asked if they would like the family member/friend who had been present nearby to come into the room while they were debriefed. Time was allowed for the researcher to answer any questions they had. All participants were asked and confirmed that they would like to receive a summary of the findings.

Immediately after the interview, the researcher reflected on the interview process and recorded their thoughts in a reflective journal. The researcher documented feelings experienced before, during, and after the interview, thoughts about how the information had affected them and influenced the questions asked, contextual and relationship factors, and general observations that might not be apparent from the audio recording but might have implications for the interpretation of the narrative (i.e. facial expressions, points where someone entered/passed near to the room etc.).

2.5.3 The Interview Structure: Development of the Interview Guide & Photo Elicitation

As noted by Riessman (2008), the vast majority of narrative studies conducted within the human sciences use research interviews to gather data. Within the context of NI, the interview, like many other aspects of the research process, is informed by the way in which 'narrative' is defined (Squire, 2008). Thus, those who perceive a narrative as being something within the person tend to ask a few highly structured questions. By contrast those who view narratives as co-created may engage in more active, conversational styles of interviewing (Wells, 2011). Furthermore, it is important to consider the influence that the interview setting may have on narrative production (Mishler, 1986). How the questions are informed and formulated, who is asking the questions, and marked power

differences between the interviewer and interviewee may all impact on narrative production (Mishler, 1986). Concerning the latter, such a power differential may be particularly evident in the context of an adult interviewing a young person (Drew, Duncan, & Sawyer, 2010).

Holding these methodological considerations in mind it was felt that a single, lightly structured interview might best meet the needs of this investigation. Participants would initially be invited to tell their story of what it was like to be a young person with CF. Following on from this, in accordance with Kvale (2007), structure would then be provided through 'actively listening' to the flow of the story and asking questions that encouraged the participant to expand and enrich their story whilst minimising the extent to which the direction taken was influenced by the researcher (Leggett, Goodman & Dinani, 2007). Furthermore, as recommended by Riessman (1993), several topics were chosen with general probes for each. This was to facilitate narrative production and to reduce the likelihood that the young people being interviewed may become frustrated and tired with the process, which as noted by Steward and Steward (1996) is a limitation of using unstructured interviews with young people.

As the research was exploratory (therefore it was not possible to draw on a pre-existing interview guide), the interview topics were informed by the research questions and the literature review. They aimed to encourage the young person to describe what it meant to them to be a young person with CF, and how their perceptions may have changed over time, or in response to broader societal narratives. Nevertheless, it was recognised that introducing structure via the use of a topic guide was in some way imposing the researcher's perception and understanding of CF on the interview through the topic areas and probes being used. Consequently, it was felt that for the stories of the young people to truly reflect what was important to them, it was necessary to provide them with greater opportunity to lead the interview. A review of the literature highlighted photo-elicitation as a possible answer to this problem.

Since the end of the nineteenth century, researchers within the social sciences have recognised the potential benefits of using photographs to explore anthropological, social, and psychological phenomena (Robinson, 2002). More recently, this has been captured within techniques such as Photovoice (Carlson, Engebretson, & Chamberlain, 2006; Streng et al., 2004; Wang, Cash, & Powers, 2000; Wang, Yi, Tao, & Carovano, 1998) and photo-elicitation (Clark-Ibanez, 2007; Collier, 1967; Fleury, Keller, & Perez, 2009; Harper, 2002; Oliffe & Bottorff, 2007; Packard, 2008; Punch, 2002; Radley & Taylor, 2003; Rasmussen, 2004; Samuels, 2007; Stuckey & Tisdell, 2010). The latter employs photographs generated by the researcher or participant to facilitate the interview process, the assumption being that photos may communicate something that may can be lost in the research

process (Clark-Ibanez, 2007). Indeed, it has been argued that photos may provide a technique for “bridging the culturally distinct worlds of the researcher and the researched” (Samuels, 2007, p. 199). Moreover, when taken by the participant, photos may empower the interviewee, providing them with greater control over the research process (Robinson, 2002).

A number of studies have explored the use of photo-elicitation with young people (e.g. Clark, 1999; Clark-Ibanez, 2007; Drew, Duncan, & Sawyer, 2010; Rasmussen, 2004; Samuels, 2007). Drew and colleagues (2010) noted that while the use of photo-elicitation required more time and effort on the part of the researchers than standard interview techniques, the technique facilitated rich, detailed information about topics which might not otherwise have been discussed, and fostered a positive attitudes towards the research process in the young participants. Furthermore, Clark (2003) who has used photo-elicitation widely in research into young peoples’ experience of diabetes described how “such methods address power asymmetries in research by ceding more control to the young person” (p. 157). Consequently, photo-elicitation may provide a useful alternative to traditional methods of interview that better meet the needs of young people.

Consequently, alongside the topic guide, participants would be invited to bring along 10-15 photos which they may use to help them in telling their story of what it is like to be a young person with CF. Within the interview, participants would be invited to choose which photos they wished to talk about, the order in which they wished to talk about them, and where in the context of the interview they wished to include them (further details of the content of the photos is provided in appendix O). It was explained to participants that the photos would be used to support the interview but that they would not be analysed or appear in the write-up of the study. The decision to only use the photos in this way was made in light of ethical concerns raised by the National Research Ethics Committee (see section 2.4.1), and also in recognition of the fact that if the photos were to be interpreted, this might diminish the sense of agency afforded through the use of the images to facilitate the interview (Robinson, 2002).

In keeping with guidance from the National Institute for Clinical Research and INVOLVE (2011) it was felt that in order to ensure the study’s relevance to the client group and to maintain transparency in the research design, it was necessary to involve young people with CF in the development of the interview plan. Consequently, a young person with CF was recruited to consult on the topic guide and overall plan for the interview (i.e. including the use of photographs to facilitate the interview). The volunteer was a white British female with CF, aged 14 years. On the basis of this, the wording of several probe questions was altered to ensure neutrality on the part of the researcher, and probes were introduced around the day-to-day experiences of a young person with CF. Feedback was also

obtained from the Supervisory team on the interview process, and from Christina Thurston¹⁹. The finished topic guide can be found in appendix K.

2.5.4 Transcribing their Stories

Narratives may be analysed in a variety of ways depending on how NI is defined (Gulich & Quasthoff, 1985), with the method of NI chosen informing the process of transcription (Riessman, 2008). Viewed in this way, the process of transcription is interpretive and must be understood as a 'partial and selective' portrayal of the actual interview (Riessman, 2002, p.11). In keeping with the position that narratives are co-constructed, and therefore the researcher plays an active role in constructing the narrative (Riessman, 2008), the interviews were transcribed verbatim, including the utterances of both the participant and researcher. Transcripts also included conversational details such as pauses, expressive sounds (e.g. laughing, sighing etc.) and overlapping or garbled speech, in accordance with guidance put forward by Poland (2002), to capture the narrative performance and clarify meaning. Furthermore, the researcher made notes after every session regarding their observations during the interview (e.g. facial expressions, contextual factors etc.) in an attempt to capture important details that might not be evident when listening to an audio recording. A professional transcription service was used to transcribe some of the interviews, after a confidentiality agreement was signed by the service (see appendix N)²⁰. The audio data was anonymised, with each audio labelled by a code which could be identified only by the researcher, and audio files and transcripts were password protected. All transcripts (completed by the researcher/transcript service) were read through while listening to the audio to check for accuracy.

2.5.5 Participant Review of Results

In accordance with the epistemological position of this study; that narratives are co-constructed, it was not considered appropriate to ask participants to review the findings as they are a reflection of the researcher's understanding and may not therefore be construed as the 'absolute truth'. Moreover, there may be ethical concerns with the process of member checking in that participants

¹⁹ Dr Christina Thurston had interviewed young people with CF on the subject of transition to adulthood and adult services for her thesis entitled "The Life and Transitional Experiences of Eight Young People with Cystic Fibrosis (CF)", submitted in July 2009. She advised that CF may or may not feature at the forefront of young peoples' narratives. As such, the final topic guide allowed space for the young people to determine the extent to which they wished for CF to feature in their narratives.

²⁰ Where the audios were to be sent to a transcription service, written consent was obtained from participants, who understood that the transcription service had signed a confidentiality agreement.

may find this process 'objectifying' and therefore potentially distressing (Wells, 2011). However, measures were needed to ensure that the researcher did not make intuitive leaps in the analysis which might confound the findings (Willig, 2008). As such, findings were discussed and reviewed between the chief researcher and research supervisor who has expertise in NA²¹.

2.6 ANALYSING THEIR STORIES

2.6.1 Guiding Framework

There are several approaches to NA classified in different ways (Langellier, 1989; Riessman, 2008) dependent upon the focus of the analysis. These include approaches that are concerned with *what* is said (i.e. content/thematic analysis; Lieblich et al., 1998), those concerned with the structure of the narrative and thus *how* it is said (i.e. structural analysis; Labov, 1972, 1982), and those that are more concerned with dialogic aspects of the narrative and thus, who an utterance is directed at as well as *when, why, and what* is the purpose (e.g. Bamberg, 1997, 2004; Riessman, 2004).

While structural and thematic analytic approaches have enjoyed a privileged position within the narrative field, in line with a general shift towards narratives as functional (De Fina et al., 2006) there has been increased interest in what may be learned through consideration of the performative aspects of a narrative. Many researchers (Bamberg, 1997, 2003; 2007; 2008; Bamberg & Georgakopoulou, 2008; Georgakopoulou, 2004, 2005a, 2005b, 2006, 2007a, 2007b; Greenberg & Angus, 2004; Riessman 2002, 2008) recognise that people use stories in everyday, natural situations²² "to create (and perpetuate) a sense of who they are" (Bamberg, 1997, p.379). Thus, narratives can be viewed not only as tools for reflecting on lives, but functional in the creation of a sense of who we are and how we wish to be perceived within a given time and context (Bamberg, 1997). Therefore, exploring the performative aspects of the narrative may provide insight into the identity work and meaning-making taking place.

As this study was primarily concerned with how young people with CF made sense of their illness experiences and the identity work taking place, it was useful to adopt an approach to analysis which considered the performative aspects of the narrative. Thus, the analysis was informed by the work

²¹ As noted previously while participants were not asked to review the findings, all participants asked to receive a copy of the findings on conclusion of the study. It was agreed that they would be sent a copy of the main findings that would be adapted in order to make it accessible to the young people involved.

²² As noted by Bamberg and colleagues (Bamberg, De Fina, & Schiffrin, 2010), and Taylor and Littleton (2006), an argument can be made for looking at interviews as a particular type of conversation.

of Bamberg (1997, 2004), Greenberg and Angus (2004), and Riessman (2002, 2008). This approach emphasises the performative aspects of the narrative but incorporates thematic and structural analysis, to ensure that the integrity of the narrative is maintained as it recognises that what is said and how the narrative is put together form important components of the identity work taking place (Bamberg, 1997). This approach to the analysis is in line with Smith and Sparkes (2009) who argue that the complexity of narratives mean that multiple methods of analysis are necessary in order to deepen understanding.

To ensure all interviews were analysed in equal depth, the following process was applied to each interview:

2.6.2 The Process of Analysis

All transcripts were uploaded into the MAXQDA 10 software. This was used to store data and reflective comments within one location, and to facilitate the analysis by allowing the researcher to code the data and make comparisons across narratives. As noted previously, the researcher initially read through all transcripts whilst listening to the audio to check accuracy.

Once uploaded, each narrative was analysed in turn. The first stage was for the researcher to become immersed in the narrative. To this end, each narrative was initially listened to whilst reading through the transcript to remind the researcher of the focus and overall tone of the interview. At this juncture the researcher also read through the reflective journal (see section 2.6.3) and added further comments on the interaction where it was felt that these had been lost in the transcription process. The researcher then proceeded to read through each account four times, initially reading for structure, then with focus on the performative aspects of the piece, and for the content and how this worked with or against broader cultural narratives. At each stage of analysis, reflections were recorded.

Reading for Structure and Performance: To answer the questions ‘*what aspects of the self are expressed in these narratives?*’ and ‘*how do the young people position themselves relative to themselves and others?*’ This part of the analysis was concerned with how the narrative was put together in order to achieve the narrator’s “strategic aims” (Riessman, 2008, p.77). Thus, each account was first read to ascertain how it was organised; how the stories within the narrative were woven together and how utterances were spoken. The performative aspects of the narrative were then considered drawing on the work of Greenberg and Angus (2004) and Bamberg (1997, 2004). In accordance with Greenberg and Angus (2004) the narratives were read for the emotional content

underpinning them to gain insight into how each individual may experience the stories emerging in the narrative. Alongside this, the narrative was read holding in mind the performative questions put forward by Bamberg (1997, 2004) and Riessman (2002, 2008):

1. In what kinds of stories does the narrator position him/herself?
2. Who are the characters in these stories? How are they positioned relative to one another?
3. How does the speaker perceive the researcher?
4. How do speakers position themselves to themselves?
5. How does the speaker position him/herself relative to the audience?
6. Who is the intended audience? Who are the ghostly audiences?²³
7. How did the researcher respond? How might this have influenced the development of the story and its interpretation?

Reading for content and the use of broader cultural narratives: To answer the research questions 'how do adolescents with CF make sense of their illness in narrative?' and 'how do the young people position themselves relative to the broader societal narratives available to them?' Each story was initially read for content, to identify the experiences that each young person recounted. This was in part informed by Lieblich and co-workers' (1998) idea of gaining a 'feel for the life' of the individual's story as a whole, but also by Taylor and Littleton (2006) who talk of identifying the 'biographical details', i.e. personal accounts of experiences over time, presented as part of the person's story. How the stories made use of and were positioned relative to broader narratives was then explored, informed by the assumption that this may form an important part of the identity work taking place in the co-construction of their narrative (Bamberg, 1997, 2004; Taylor & Littleton, 2006).

Comparing and Contrasting the Narrative Accounts: On completion of all levels of the analysis for all narratives, a global impression of each account was written along with a summary of the main themes²⁴ that emerged from each interview (Lieblich et al., 1998). The researcher then considered all accounts collectively, looking for similarities and differences in the emerging stories. This allowed for the production of broad storylines, within which participants adopted similar or distal positions in either the content or performance.

²³ i.e. those not in the room with whom the speaker may also wish to share their story (Langellier, 2001)

²⁴ The notion of themes is used here to refer to not only the content but also repetition in the way stories were structured and performed.

2.6.3. Reflexivity and the Reflective Journal

Reflexivity is perceived as an overarching principle of constructionist studies, and alongside transparency in the research process, contributes to the overall validity and credibility of the research findings (Spencer & Ritchie, 2012). Thus it is necessary that the researcher be attentive to their role in the research: why it is they are interested in a particular topic and how their knowledge and assumptions may shape the way they approach the interview and analysis. Consistent with this, the researcher kept a reflective journal in which entries were made before and immediately after each interview, and throughout the transcription and analysis process. These reflections then informed the analysis and subsequent discussion of the research.

2.6.4 Representing the Narratives

On completion of the analysis, the decision was made about how to represent the narratives in the write-up of the analysis. Capturing the richness of the narratives within the word constraints of the thesis was challenging as to ensure the accounts were talked about in a way that was clinically useful required illustration of the similarity and diversity between and within them. Consequently, the decision was made to begin the write-up by presenting each person to the reader and providing a global impression (Lieblich et al., 1998) of each narrative, as interpreted by the researcher, written in the third person to ensure that it was clear that these were the interpretations of the researcher (Saukko, 2000). To ensure transparency, quotes from the narratives were woven into the researcher's interpretations (Riessman, 2003).

Following this, the collective narratives were presented, with consideration of the main storylines emerging. Drawing on the notion of "stitching together" (Saukko, 2000, p.300) these storylines were interwoven with the researcher's interpretations of how these influenced and were influenced by the emotional experiences of the young people and the identity work taking place. How these accounts and subsequent interpretations were informed by wider societal and cultural narratives is also threaded through discussion of the main storylines, to demonstrate how these were entangled within the co-construction of the narratives.

As the epistemological position of this study posits that the results are not objective, the findings, and discussion were presented together to provide the reader with a coherent narrative of the researcher's interpretations and to position this within the context of existing literature. This reflects

the assumption that narratives are informed by wider narratives and situated in time and context (Murray, 2001; Wells, 2011).

2.7 CREDIBILITY, RIGOUR, AND PRAGMATIC USE OF THE STUDY

The positivist assumption, that through hypothesis testing we may access one identifiable truth, underlies traditional notions of reliability and validity. This diverges from the constructionist idea that there is no definitive 'truth' but rather a tentative and shifting interpretation of an individual's experiences which is shaped by the historical, social, and personal circumstances of those involved in the account's construction (Runyan, 1980). Consequently, the strength of a qualitative research study is determined through reference to criteria such as credibility (whether the interpretations made can be considered plausible and meaningful), rigour (whether the interpretations are supported by the original data), and pragmatic usefulness (whether the research can inform clinical practice and future research) (Polkinghorne, 1988; Riessman, 2008; Yardley, 2008). Several steps have been taken to ensure that these criteria are met.

Firstly, to ensure credibility and rigour, the author has been transparent about how the narrative was obtained, how the process of narrative construction was considered within interpretation of the narrative, and how analysis was conducted to allow the reader to judge whether the interpretations made are plausible and meaningful. In addition, a copy of the transcript for Amy's interview and details of how this was analysed are provided in appendices P-Q²⁵. This is included to allow the reader to gain a context for the narrative and consider the implications of this for the adequacy of the analysis (Wells, 2011).

Secondly, to ensure its pragmatic usefulness, the clinical relevance of this study is discussed in the introduction and conclusion sections of this thesis. Moreover, this criterion was reflected upon during the analysis and write-up of the findings. Nevertheless, the usefulness of a study is also defined by how readily accessible it is to the relevant communities (Riessman, 2008). Thus, it is the responsibility of the author to ensure that the research is widely disseminated. To this end, an abstract has been submitted to the Paediatric Psychology Network Conference with the hope that the findings of this study may be presented to professionals and researchers working with young

²⁵ Amy provided additional consent for the full transcript of her account to appear in the examiner's copy of this thesis.

people with chronic illness. Furthermore, a journal ready version of this study has been written (see portfolio) which will be submitted for publication in a peer reviewed journal.

CHAPTER 3: FINDINGS & DISCUSSION

3.1 OVERVIEW

This chapter contains the interpretation of the co-constructed narratives of six young people on their experiences of living with Cystic Fibrosis (CF). All participants were given pseudonyms to maintain anonymity, and identifying information within their accounts was changed. The NA is presented in two parts. The first provides a summary of the demographic information and circumstances of the interview, to provide the reader with a framework in which to position the interpretations. This is consistent with the stance that all narratives are co-constructed and occur within a time and context (Murray, 2001; Wells, 2011). Within this section, a 'global impression' of the interpretation of each individual narrative is presented (Lieblich et al., 1998) to provide the reader with the researcher's overall impressions.

The second part of the analysis presents the collective storylines emerging from the narratives and considers deviant or counter narratives to these. Drawing on the metaphor of 'quilting' (Deleuze & Guattari, 1987; Saukko, 2000), these storylines will be interwoven with interpretations of the emotional experiences of the young people and the identity work occurring, and connections will be made to the existing literature to present epistemological narratives (Harling Stalker, 2009). While this way of data presentation differs from traditional methods, it is consistent with the narrative approach, allowing the results to be understood in the context of the wider narratives that pertain to this area of inquiry²⁶.

Quotes from the narratives of participants are shown in italics.

3.2 INTRODUCTION TO THE PARTICIPANTS AND A 'GLOBAL IMPRESSION' OF THE INDIVIDUAL NARRATIVES

3.2.1 Amy (16years, White British)

²⁶ This approach to presenting the findings is also consistent with the work of other qualitative researchers (e.g. Guell, 2007; Jessup & Parkinson, 2010).

Amy lived in the South of England with her parents and younger sister. She was in Year 11 at school, preparing for her GCSEs. She had been diagnosed with CF pre-natally, and experienced yearly bouts of ill-health and subsequent hospitalisation until she was 5 years old, though had only been admitted to hospital twice since, and talked of being 'well' with her CF. Nevertheless, the interview coincided with a hospital admission owing to a chest infection which had not responded to oral medication. The interview took place on a busy 8-bay children's ward. She was situated in the middle of a row of bays. When I arrived, Amy was sat on the bed, chatting to her mother. The interview was interrupted four times, the last of which was a 10 minute visit from the physiotherapist.

Global Impression

Amy's account portrayed an identity of someone who was healthy and in control of her CF. Her preferred position appeared to be that of a normal teenager, able to do everything her peers could. However she also talked of CF as part of her normality, something she did not "*think about that much*" and was able to "*forget about*", although she acknowledged times when CF interfered with doing what she wanted. Amy endeavoured to present an account of herself that was consistent with her story of "*not worrying about it [CF]*", though there were times within the co-construction of her narrative that her demeanour changed in a way which suggested underlying worry. Amy sometimes acknowledged this worry while at other times she brushed over her emotional experiences, following them by saying "*but yeah*", (e.g. when talking about a relationship break-up she noted "*It's really hard coz [...] it's a bit weird (.) but yeah*"). Amy would also move the conversation on by moving to the next photograph, suggesting that such topics were inconsistent with her preferred identity of someone who was unconcerned by illness. These attempts to remain light-hearted and portray herself as undaunted by CF seemed to be linked to the idea of putting on a brave face, though it was not clear from her account for whom she was being brave.

Amy's narrative highlighted how peers' nonchalance towards her CF helped her to accept it. She positioned herself as surrounded by a supportive network of friends and family who let her get on with life but offered support at times of illness. Nevertheless, the way she talked of being open and gaining support from others suggested that she sought support for the practical management of CF, with little talk of her emotional experience. This is consistent with the idea of needing to put on a brave face, that she felt that she could not complain about the CF to those around her, including me

²⁷ Where words have been taken out, this is represented by "[...]". Numbers in brackets indicate length of pause in seconds. If the pause was less than a second in length, this is represented as "(.)". Where emphasis was used, words are underlined.

as the researcher. This may in part be explained by her expressed annoyance towards those who might “*make a big deal out of it*”, who she talked of as imposing limitations on her owing to their preconceived idea that CF was a “*big thing*”. Thus it seemed that to acknowledge and talk about unpleasant feelings that might arise in relation to the CF would be acknowledging that at times, CF was a big thing.

3.2.2 Miranda (12years, White British)

Miranda lived in the East of England with her parents, and two siblings. She was in Year 7 at school. She had received a diagnosis of CF aged two years. She had suffered with blockages of her bowel caused by lipomas (lumps of fatty tissue) until aged nine, and received surgery to rectify the problem. Though she was regularly admitted to hospital in early childhood, Miranda noted that she had never had to stay overnight in hospital because of her CF and described herself as healthy. When I arrived at her house to conduct the interview, Miranda was playing outside with her siblings and new puppy. She brought in her puppy to meet me and we spent some time chatting prior to the interview. The interview took place in the playroom, allowing for a confidential conversation.

Global Impression

Miranda’s narrative was richly detailed, punctuated by short stories and anecdotes of her childhood and present day experiences, and talking at length about her hopes and fears for the future. Throughout her account, Miranda aligned herself with her peers and broader adolescent narratives of hating homework and finding lessons boring. However she also differentiated herself from those girls who were “*really quite silly...just bring in massive make-up bags and talk about boys*” and portrayed an image of someone who understood that “*if I work hard...I’ll be able to get better education and better well paid job*”. She also presented herself as someone who stood up for herself and others, as she talked of getting revenge on her brother and cousin, and defending her friends.

Miranda’s account was generally light-hearted and served to engage and entertain me both through the content (e.g. anecdotes about her family and teachers) and performance of her stories (e.g. putting on voices and making fun of herself). However, as the interview progressed, use of the photos led to talk around her concerns for the future or stories of being alone in the dark, and talk about feeling scared or anxious which was reflected in the pace and tone in which these particular stories were told. The cause of her anxiety was often attributed to “*stuff in the news*” rather than

tangible aspects of her life. The one exception to this was her concerns about how CF might impact on her future which she talked about towards the end of her account. At this juncture, she seemed to find it harder to sit with this anxiety presenting reasons why she did not need to worry such as *“there’s a lot of people that ... are well and healthy an- in their fifties”* and *“I’m quite healthy (1) at the moment so hopefully (.) I’ll be able to le-live a normal life (.) up to (.) I’m old”*. These statements may have been said in an attempt to reassure herself or a ghostly audience (Minister, 1991) such as her family or friends, or to present a preferred identity to me that was in keeping with her earlier description of CF as something that *“doesn’t really matter to me”* which she ascribed to the fact that *“I’m just used to it”*.

3.2.3 Claudia (13years, White British of Italian and English Heritage)

Claudia lived in the East of England with her parents. She noted that she had two half-sisters whom she saw regularly. Claudia was in Year 8 at school. She had received a diagnosis of CF at birth and reported only two episodes of infection, one of which occurred towards the end of the previous year and resulted in a hospital admission. She talked of herself as being well. On first meeting Claudia I had the impression of someone much older, closer to 15/16 years. She was softly spoken but appeared confident in her mannerisms. The interview took place in the living room of the house which was separate from areas of the house where her mother was present, allowing for a confidential conversation.

Global Impression

Claudia’s account was heavily situated in the present, with little talk of her past or future. Regarding her past, Claudia volunteered little, using only brief references to her recent past to contextualise events in the present. When asked about her childhood, she appeared to find it difficult to answer which she justified by saying she had *“a really bad memory”*. It is poignant therefore that the stories she did tell about her past related to her experiences of having CF: of hospital admissions, routine appointments, and of having injections, events that may have been emotionally salient for her and thus more memorable. When asked directly about her thoughts about the future, she noted *“I don’t really think about the future”*, a position which was consistent with the structure and content of the account.

Within her stories, Claudia positioned herself as surrounded by people. The first third of her account was predominated by stories of her relationships with friends and family, within which she portrayed herself as “caring”, “fun”, and as “look[ing] out” for others. She talked of “having fun” as being important in her life and positioned this as more important to her than her CF, a stance that was reflected in how little she talked about CF. Interestingly however, on the occasions that CF was talked about, she was the one to bring it into conversation. Her tone and mannerisms during these stories suggested she felt comfortable talking about CF, portraying it as an accepted part of her self-image, which existed in the background.

3.2.4 Rob (15years, White British)

Rob lived in the East of England with his parents. He noted that he had two older siblings who no longer lived at home. Rob was in year 11 at school and preparing to take his GCSEs. Having been diagnosed with CF at birth, he had experienced only two hospital admissions during his life. He described himself as fit and healthy. The interview was initially rescheduled by his mother as Rob had been suffering with a cold. As such, I met with him a week later than planned on a Saturday afternoon, to conduct the interview. The interview took place in a guest bedroom just off the main entry hall to the house. Though it was unlikely that the conversation was overheard, his family were often heard walking past or shouting to one another, which may have influenced the extent to which Rob felt able to discuss more sensitive issues.

Global Impression

Throughout his account, Rob portrayed himself as having the identity of a normal teenager, able to do the things his peers were doing in the present, and aspiring towards similar goals for the future including being more independent from parents and going to University. To tell this story he drew on a number of societal narratives about how teenagers relate to their peers and parents, and the steps taken in the transition process. Alongside this account he identified himself as someone who was “laidback” and “chill-axed”. His stories contained reference to this across context and time, and the way in which he performed his account was consistent with this identity, making his account of “going with the flow” quite persuasive.

Consistent with the portrayal of himself as going with the flow, Rob spoke of CF as something he “didn’t think about much” and which generally “doesn’t stop me doing what my friends do”. In his

stories of CF he positioned himself among characters that were “*laidback*” about CF and understood that he “*didn’t really talk about it*”, helping him to hold onto the laidback attitude he had towards it. Nevertheless within this story, CF and more specifically, taking his medication was said to sometimes interfere with “*having fun*”. Indeed Rob talked of the medication as being the only thing that separated him from his peers as was conveyed clearly in his closing statement:

RA: [...] if you had (.) a message for (.) the world (.) about what it’s like to be a young person with CF (.) what would that message be?

Rob: [...] that it’s not really a big deal (.) you’re pretty much the same just (.) do a bit of medicine now and again

3.2.5 Daniel (12years, White British)

Daniel lived in the East of England with his parents, and two younger siblings. He was in Year 8 at school. Daniel was diagnosed with CF prenatally and was born 11-weeks premature. He experienced problems with reflux as an infant which meant he was tube fed until 2years of age. He talked of having a scar on his stomach because of this. Concerning CF he noted three infections which he described as “*colds*” and reported only one hospital admission. He described himself as fit. When I arrived Daniel was outside playing with his younger brother. The interview took place in the dining room. We were interrupted twice, initially by his younger sister, and later by his mother. Throughout the interview Daniel fidgeted in his seat, appearing to find it difficult to sit still. As his mother noted that she was concerned he might have an attentional deficit, this behaviour might be indicative of difficulties attending, although this was not overtly apparent in the way he told his stories.

Global Impression

Daniel told his narrative in a way that engaged and entertained: speaking with pace, and giving short answers. This was accompanied by energy and exaggerated facial expressions, which often had me laughing. Though there were few self-statements or evaluations in his account, those presented were often humorous self-deprecations. I found myself warming to him as he made these statements, and wondered if this allowed him to connect with others, exposing his vulnerabilities behind a veil of humour. Consistent with this, Daniel presented himself as a joker and as somewhat mischievous but also as someone who could be responsible and “*a nice child*” within the roles of the older sibling and managing his treatment. Throughout the narrative, Daniel drew on the dominant

discourses of being a teenager and appeared to position himself within the norm, alluding to shared interests with peers, hopes for the future, and attempts to gain more independence from his family.

Concerning his relationship with CF, Daniel talked of himself as not really thinking about CF though he reported seeing his treatment as important, as something he had to “*do it daily (.) three times a day*” because not doing it “*will make you ill*”. Indeed, throughout the account, CF was only mentioned briefly. By contrast, his narrative was dominated by talk of medication, which featured in stories of being more independent and of CF as an annoyance. The health professionals involved in his care may have been a ghostly audience (Minister, 1991) to his account of his medication as he demonstrated his knowledge of and adherence to his treatment. However, at times the way in which these stories were told seemed designed to entertain or impress me, as for example, he spoke of being able to take his tablets “*17 at once*” and appeared eager to let me know that part of his nebuliser cost “*three grand*”.

3.2.6 Sara (14years, White British of European Heritage)

Sara was living in the East of England with her mother, grandmother, and sister. This was described as a temporary arrangement following the break-up of her parents’ marriage. Sara noted that she was diagnosed with CF as an infant, and spent a lot of time in hospital owing to CF during childhood. Despite this she described herself as well. The interview took place on a Saturday morning in the conservatory of the house. When I arrived, Sara was still in bed. She emerged after 20 minutes with prompting from her grandmother. We spent some time chatting prior to the interview.

Global Impression

Sara identified herself as a “*happy person*” who was a bit “*mad and crazy*” and liked to “*have fun because like you don’t really want to just sit around and not be happy about something*”. Throughout her narrative, she gave many examples of times when she and others had perceived her in this way. Nevertheless, this appeared in stark contrast to the stories she told of the difficulties faced by her family, which she spoke about as being a source of upset and disruption in her life. Though CF played a significant role in her narrative, this was talked about as secondary to the family situation and as something that “*didn’t really come up*”. This was at odds with her account of having been in hospital approximately every three months since the age of four years. However, she contrasted her experiences of CF against those of young people who were dependent on oxygen and confined to a

wheelchair. Thus, she positioned herself as “*lucky*” and because of this saw it as important to “*not just waste it [time] away and not do anything or be unhappy about one thing for ages*”.

Sara’s family circumstances and ill health meant that she had not attended school fulltime since the start of the school year. This may have contributed to the fact that her narrative contained little talk of school or peers. Similar to other participants she was heard to draw on dominant cultural narratives of “normal teenage” life: wanting greater independence from parents and hoping to obtain work in the future. She would downplay or move on from stories that were inconsistent with this narrative such as those around not going to school and having nobody around (outside of her family) who she perceived as a friend.

3.3 EMERGING STORYLINES

This section presents my interpretation of the collective storylines, emotional experiences, and identity work emerging within the narratives. A quilting metaphor (Deleuze & Guattari, 1987; Saukko, 2000) is used to illustrate how these parts of the analysis are entwined (summarised in figure 1). Emotional experience is talked about as one of the strands woven through the storylines, consistent with the idea that this serves an organising role in human experience (Greenberg & Angus, 2004; Greenberg & Pascal-Leone, 2001). The other strand woven through the storylines is the identity work taking place, as the narrator chooses to tell of experiences, and to tell them in a way that is consistent with a preferred sense of self. Finally, the local and broader context in which the narrative is co-constructed forms the thread that holds the narrative together, presented as a dashed line in figure 1. This section will begin with analysis of storylines of childhood experiences, following with analysis of stories of life in the here-and-now, and finally storylines of the future, attending to the threads that hold them together throughout.

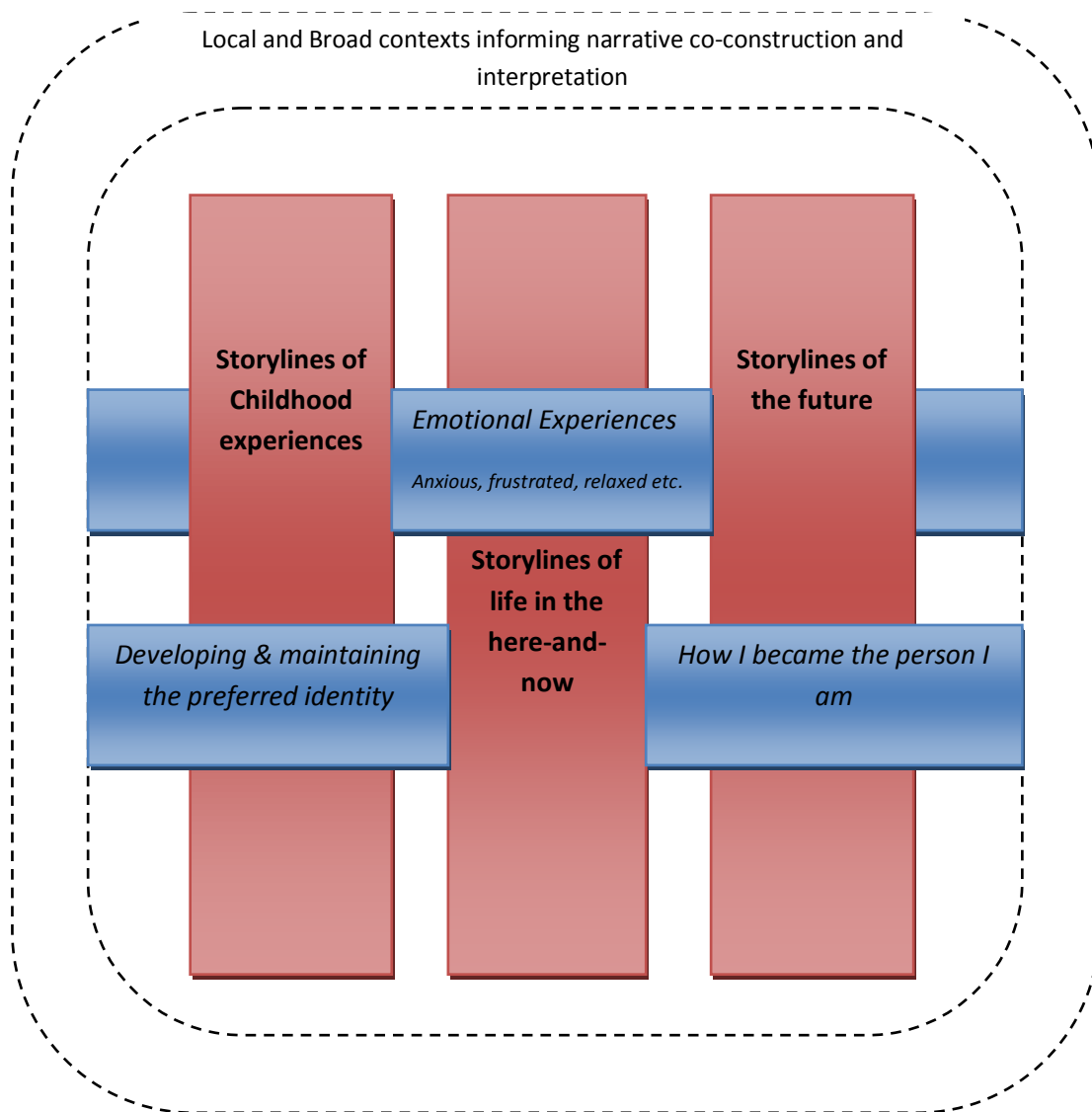


Figure 1: Diagrammatic summary of the way in which the analysis of storylines is discussed

3.3.1 Storylines of Childhood Experiences

At the outset of the interview, participants were asked to tell me “a bit about what life’s like for you [...] what kind of things you like doing? (.) who’s important in your life (.) that kind of thing...”.

Perhaps unsurprisingly, all started their narratives in the present²⁸. Nevertheless, all participants gave some account of their past. With the exception of Miranda who spoke about her experiences with family and friends in her stories of childhood, talk of early experiences focussed on those of CF. It is likely that this was influenced by their expectations of the interview: that they were there to talk about CF. Nevertheless my questions might also have influenced their narratives, as I only asked directly about their childhood experiences of CF.

While some gave in-depth accounts of their childhood experiences of CF, others glanced over them, using them to make sense of their stories of the present. Claudia in particular presented few stories of the past though those that were included described emotionally salient experiences. Amy and Sara also chose to present stories of their past with CF that were laden with anxiety or sadness. The emotionally rich accounts the participants gave of their early experiences of CF contrasted with the light-hearted tone adopted in talk of their experiences of CF in the present. The possible reasons for this are discussed in more detail later in this section.

The main stories of childhood experiences of CF were around learning about CF, making sense of CF through interactions with others, and early memories of treatment and hospital. These storylines are discussed below.

Learning about CF

As noted by Greenhalgh and Hurwitz (1988) adult illness narratives typically begin with the story of illness onset or an account of the period prior to diagnosis, which is contrasted with the impact of illness. Stories of onset have also been ascribed importance in the illness narratives of children (Guell, 2007; Woodgate, 2005) as the point at which the young person begins to make sense of their experiences in cases where the child may have experienced unexplained symptoms (Guell, 2007), or as a turning point in the child's life which leads them to see themselves as different (Woodgate, 2005). By contrast, only half of the participants told stories of how they learned of their CF. Moreover, those that did, placed little emphasis on these stories and told them in response to a direct question, prompting the question: would they have told these stories had they not been asked?

Where stories of learning about CF were told, the young people in this study spoke of their diagnosis "*being explained*" to them by their parents. This is consistent with recent research which found that

²⁸ This is considered in more detail in section 3.3.2

the parents of children with CF recalled having explained the diagnosis to their children (Jessup & Parkinson, 2010). Those young people that included stories of learning about CF spoke of having little awareness that their experiences up until that point were anything other than normal. For example, Amy noted that:

Amy: I just thought it was (.) just my life and (.) then (.) and then (.) mum explained it to me and I was like (.) "oh" (.) she's like "so this is different to other people"

Amy's talk of her experiences of CF as part of life suggest that it was viewed through a *normalcy lens* (Robinson, 1993) which her account suggested was fostered by her family. Consequently, for Amy, learning about CF brought with it the understanding that she was different, as she described a feeling of being "out of other people". This is consistent with the findings of Woodgate (2005) who reported that in the illness narratives of young people with cancer, finding out about the diagnosis brought with it a sense of difference from others. Nevertheless, it contrasts with previous research into the experiences of growing-up with CF in which young people reported that realising they had the label of CF meant little to them (Christian & D'Auria, 1997). The findings of Christian and D'Auria are however more consistent with the stories told by Rob and Sara, who described this as not being a cause for concern. For example, when asked how she learned she had CF, Sara paused for eleven seconds before stating:

Sara: I think umm...she [her mother] explained it to me as I know that I went into hospital before (coughs) and (.) I think the more she explained it as in I've got CF (.) and it's life threatening (.) but like nobody else can catch it or anything

RA: Okay (.) Can you remember how that felt for you to hear that and to learn that?

Sara: Umm...I felt fine by it (.) umm ... it never really bothered me that much

Consistent with the ideas of Charmaz (2002), the long pause prior to her answer might indicate an absence of a story. Thus, as stated, learning about CF may not have been something Sara was "bothered" about. However, consistent with the literature on 'trouble' in identity work this pause might have signified that work was taking place to ensure that her account of learning of CF was consistent with her preferred identity (Taylor, 2005) or difficulties constructing her story within the context of the interview. This was reflected in her talk about how CF was explained to her which

captured the salient aspects of this experience. Sara reported that learning of CF for her meant learning that she had a life threatening illness that was not contagious. This was consistent with her preferred identity of caring for others and being thankful for her health.

Turning to those accounts which did not include stories of how they learned they had CF, when taken in the context of their accounts the absence of this story was consistent with how they position themselves relative to CF. For example, the structure of Claudia's narrative appeared to position CF as something that was in the background. Thus, it may be that she did not recall how she learned about CF or that telling this story would have been inconsistent with this position. For Miranda and Daniel, other childhood experiences of illness appeared to take precedence over those of CF and therefore learning about CF may have been less important to them than making sense of their other illness experiences. Taken together, these findings indicate that for most of the young people in this study, their experiences of learning about CF were not described as the pivotal moment that might be expected for those diagnosed with other conditions where the diagnosis comes later in childhood or adulthood (e.g. Frank, 1995; Greenhalgh & Hurwitz, 1988; Guell, 2007; Woodgate, 2005).

Making Sense of CF through Interactions with Others

Using a grounded theory approach to explore young peoples' reflections on growing-up with CF, Christian and D'Auria (1997), found children were often unprepared for the negativity they received on disclosing a diagnosis of CF and that this added to the feeling of difference and needing to keep secrets. This finding differs from that of the present narrative study, as all participants spoke of others as *"not making a big deal"* of the diagnosis and said that their friends were *"not fussed"* about CF. This attitude was ascribed to peers by all participants and was spoken about by some as linked to the process of making sense of their illness. In the context of taking his medication in public, Rob spoke of how his attitude to CF had shaped that of friends, stating *"probably coz I was laid back about it (.) they don't really (.) think it's a big deal"*. Thus it seemed that Rob's *"laidback"* attitude to CF and his treatment helped his friends to accept his diagnosis. He later talked about how he developed this relaxed attitude, stating that it was *"probably through my friends (.) just grew up being chill-axed"*, constructing a circular pattern in the development of a relaxed attitude to CF, with Rob and his peers developing an understanding of CF through their interactions. Amy talked about her experiences in a similar way, stating that:

Amy: *I thought they [friends] were gonna be like (.) “oh no (.) she has CF don’t talk to her” and stuff like that but they didn’t care (.) so I was like “oh” (.) and then I started being really laid back about it”*

Amy’s narrative indicates that through her friends’ acceptance of CF she learned to accept this part of herself. Amy may have told this story in order to present a preferred identity of herself as someone who was accepted and popular, and may have been keen to be seen by me as popular also. Within the context of the interview, Amy, and Rob, might have found it difficult to talk about stories that contradicted this preferred identity. Nevertheless, these accounts offer important insight into the process of acceptance, which previous research has shown to be important for wellbeing in young people with chronic illness in general (Kintner, 1997), and with CF more specifically (Casier et al., 2011; Ernst et al., 2010). Indeed, the findings of this study suggest that for some young people with CF, the way peers respond to their CF may play a vital role in how they integrate CF with their sense of self.

Early Experiences of Illness; Treatment and Going into Hospital

For many young people with chronic illnesses, early experiences of hospitalisation or (painful) treatments are memorable events in the child’s illness experience (Chen, Zeltzer, Craske, & Katz, 2000; Merritt, Ornstein, & Spicker, 1994). Accordingly, many of the young people in this study told stories of being scared, anxious, or frustrated at having to go into hospital or receiving treatment. However the way in which these stories were told and positioned relative to stories of the present is of particular interest. Turning our attention first to the stories told of childhood experiences of treatment and hospital, Amy spoke of being scared of needles when she was a child:

Amy: *[...] when I was younger like (.) I never used to like it so there used to be like ten (.) no not ten (.) two three doctors holding me down and like sticking needles in me-e-e (.) and it was really horrible (.) and it sort of basically traumatised me*

Throughout this story, Amy’s speech was hurried, portraying some of the anxiety she talked about. Moreover, the language used: her exaggeration of the number of doctors “*sticking needles*” in her, which she evaluated as “*horrible*” and having “*traumatised*” her, was highly emotive, conveying the fear that she described experiencing as a child. Similarly, Claudia, told how she used to “*hate having*

cannula's in my hands and like IVs²⁹", stating that *"it just really really hurt"*. Her repetition of the word *"really"* and her sombre tone of voice conveyed the emotion attached to these early treatment experiences.

Sara told emotion laden stories about her early experiences of hospitalisation. She described how she *"never used to like it [hospital]"* owing to the fact that *"probably because when you're young (.) you think you're going into a skeleton place"*. Her tone of voice during this story conveyed a sense of sympathy towards her child self, suggesting that this was a difficult experience for her. However, the way she emphasised the word *"skeleton"* took on a mocking tone, positioning this fear as a childhood fear and something with which she no longer identified.

The steps taken by Sara to distance herself from the image of herself as someone who was fearful of going into hospital was mirrored in the narratives of Amy and Claudia. Amy's story of being scared of needles was followed immediately by an account of how she had learned to manage her fear of needles through therapy. Similarly, Claudia spoke of no longer using *"the cream³⁰"* to take away the pain of injections owing to the fact that *"in year eight we have to have like a cervical cancer injection (.) so I was like (.) I need to start doing it without the cream now"*. Claudia's account was interesting as it indicated an awareness of broader societal narratives: that it was acceptable for her to be scared of needles as a child, but not as a young person. It is possible therefore that her peers or society were the ghostly audiences to this story (Minister, 1991), as she positioned herself as able to manage the pain she ascribed to needles. A similar pattern can be perceived for Amy and Sara as they placed their stories of being scared in the past, allowing them to position themselves as overcoming adversity, drawing on quest narratives of illness (Frank, 1995). Moreover, in doing this, they moved themselves into the position of not being concerned by their illness, which is consistent with the image of themselves portrayed in talk of the present.

Positioning themselves in this way, there was a sense that while it was acceptable to acknowledge uncomfortable emotions in the past-tense, it was not acceptable to do this in the present. Indeed, throughout all the young peoples' accounts, there was an absence of negative emotions when speaking about their experiences of the present or future³¹. For Rob and Daniel, this absence of emotion was apparent throughout their accounts, as neither acknowledged having experienced any distress in relation to their childhood experiences of illness. This may be attributed to the fact that both reported having had few periods of 'illness' with their CF and thus, no periods of distress. However, the difference between the boys and girls in this sample could reflect a more general

²⁹ Intravenous line used to administer antibiotics to treat an infection

³⁰ Emla cream used to numb injection sites

³¹ This is talked about in greater detail in section 3.3.2, CF as a continuation of the norm

gender difference in the way they made sense of their illness experiences and in the extent to which they were willing to acknowledge the emotional difficulties that might be associated with CF, which might be influenced by dominant narratives around the expression of emotion by boys (for review see Courtenay, 2003). The findings of several studies also suggest that men are less likely to report distress to female health professionals (Levine & DeSimone, 1991; Puntillo & Weiss, 1994), thus my gender may have influenced how able the boys were to acknowledge their emotional experiences.

3.3.2 Storylines of the Here-and-Now

A focus on the present dominated all accounts and may have reflected the participants' preoccupation with their current situation, as documented in other adolescent accounts of illness (Sawyer & Aroni, 2005; Timms & Lowes, 1999). However the aims of the research (detailed in the participant information sheet), and the instruction that they should obtain photos depicting "*what it is like to be you, as a young person with CF*" may have contributed to a focus on the present. Using photo elicitation led many of the participants to produce short, delimited narratives of their daily experiences. For example, Rob chose to present a series of photos that represented disparate aspects of his life, which influenced the construction of his narrative as he focused on the content of the photo. This was also the case for Daniel, Sara, and Claudia, who tended to stay close to the subject of each photo. As the photos were of their day-to-day experiences, this may have limited the extent to which these young people felt able to tell stories about the past and the future. This may be a criticism of using photo elicitation in the production of narratives, as also noted in a review by Robinson (2002).

A number of storylines emerged around everyday life. All participants told stories about their continued experiences of CF including how it influenced their lives, though most talked of this as just one part of their lives. Their accounts were primarily concerned with their relationships with others, and presenting themselves as normal teenagers, the role of which is discussed below.

CF as a Continuation of the Norm

All participants presented a story of CF in adolescence as *just* a part of their lives and as such, a continuation of *their* norm. That this was true of all participants from early to mid-adolescence extends the work of Williams et al. (2009) who noted that younger children were likely to use a self-

referentially based “normal to me” way of thinking about CF and that consequently, no revision of aspirations and life are required. For example, Miranda spoke of how:

Miranda: It's [CF] there (.) but I wouldn't (2) I've had it for now twelve years (.) so (.) I'm just used to it (.) um (.) maybe if (.) I (2) was diagnosed with CF like in year...year five (.) then maybe (.) maybe it would be worse (.) but coz I've had it (.) since I was a baby (.) then it (.) doesn't really matter to me ...

Miranda's comment on how she saw CF was prompted by my reflection that CF was mentioned only briefly during her account. Thus the way her account was structured was consistent with her stance on CF as something she was used to. Miranda's comment that it might be different had she been diagnosed recently was echoed by Amy, who stated:

Amy: like if I found out I had to do it now (.) I'd be like (.) "Oh my God" (.) (laughs) I don't want to do that (.) but coz I done it my whole life (.) I don't really (.) see it as a routine (.)

Arguably both showed an awareness of broader societal narratives around the challenges of adjusting to illness (Frank, 1995; Lawton, 2003), and adopted a counter-narrative of CF as being part of their norm because they had never known anything different. Amy's story of CF as her norm was told in the context of taking medication, and is consistent with previous research which has shown that for young people with CF 'normal' can include medication as a matter of course (Badlan, 2006).

Claudia also talked of her medication in this way, stating “*Well I think it's because I have got so used to like taking it and stuff (.) it's not like the biggest thing in my life anymore*”. Her use of the word “*anymore*” allows for the interpretation that this was not always the case but that she came to see this as her norm during her life, positioning her as having overcome adversity. Nevertheless, this statement was congruous with how she spoke about CF, weaving it through the co-constructed narrative indicating that for her, CF and medication were simply part of life.

Sara's stories of CF were also interwoven through those of being a normal teenager, positioning CF as something that was an everyday part of life. In contrast to the others however, she talked of regular hospital admissions as part of her norm. She laughed as she spoke about going into hospital every two-to-three months for treatment since the age of four, saying “*so I know the hospital pretty*

well” and elaborating her account by providing names of the ward staff with whom she had become familiar. This differs from Badlan (2006) who, using an IPA approach to explore young people’s subjective experiences of living with CF, found that young people tended to reserve the idea of being ‘unhealthy’ and thus ‘different’ for times of ‘illness’ such as infection and hospitalisation. For Sara however, it seemed that owing to the frequency of her hospital visits, this too, had been integrated into her idea of what was normal for her.

In constructing CF as a continuation of their norm, participants positioned themselves as having a relaxed attitude to CF. Claudia noted *“it’s not like the biggest thing in my life”*. Rob talked about going *“with the flow”*, while Sara stated that it was important not to *“waste any time”* by being *“unhappy about just one thing for ages”*. However, perhaps in an attempt to acknowledge the dominant narrative of illness impacting on life, they also spoke of the times when CF had interfered with the lives they wanted to lead. Rob, who reported only two incidences of illness, talked of treatment as being the aspect of CF that got in the way of doing what he wanted and how things could be better if his treatment regimen took less time, seeing time doing treatment as time that could be spent having fun; *“[...] waste half an hour of the party (.) when I could be partying”*.

Rob described his experiences of treatment getting in the way as *“annoying”*, though his tone throughout the story was light-hearted, jokingly demonstrating to me how he was able to continue to play computer games while doing his treatment. A similar story was also told by Daniel, who when talking of doing his medication noted *“I don’t want to do it (.) I wanted to go back to what I’m doing”*, which he described as watching TV or playing on his PlayStation. Again, he demonstrated to me how he had learned to do his treatment and continue playing games, stating:

Daniel: [...] Sometimes you can play on your PlayStation while doing it (.) so you have to hold it like that (.) and do the thing up (demonstrated how he held the control pad and nebuliser in a way that allowed him to see and play his game)

Through their accounts, Daniel and Rob seemed keen to show that while CF impacted on their lives, it was *“not really a big deal”* (Rob), portraying an image of themselves as *“still do[ing] those things”* (Daniel) that they wanted to do. Moreover, further into his account of the impact of CF on his life, Daniel spoke of CF as having positive implications as he noted in his story of having an IV put in that he *“Uhh missed a day off school (smiled)”*, which he talked of as a good thing. This idea also emerged

in the stories told by Claudia and Sara. For example, in response to a question about her appointments to monitor her CF, the following exchange took place between Claudia and I:

Claudia: Yes I get to miss school (laughs)

RA: So when you said that was kind of "I get to miss school" (.) it was quite a good thing?

Claudia: Yeah (laughs)

RA: Why is it such a kind of positive thing?

Claudia: Because (.) I always go for a check up on a Wednesday because that's when the CF clinic is (.) and (.) I have lessons I don't like on a Wednesday

Claudia described having to miss school as something that she was pleased about, making light of the impact CF had on her life. Through these stories, the young people acknowledged that CF might impact on their lives but maintained a preferred position of being unconcerned by this. Their talk of the benefits of missing school may arguably be construed as 'making the best of the situation' which was a theme which emerged as an adaptive strategy in young people diagnosed with cancer (Woodgate, 1998). Moreover, talking of missing school as a benefit to CF also positioned them as sharing the views of their peers: that school was something that was imposed on them rather than something they enjoyed. Thus it seemed, that it was important for the young people to be seen as unconcerned by the limitations imposed on them by CF. Moreover, there was a tendency for the young people to brush over stories which might contradict this position, and a tendency for me to go along with this process³². For example, Amy appeared to use the photos to change the topic of conversation when it became uncomfortable. When talking about the transition to college, though the content of Amy's speech positioned her as not being worried, her tone of voice and pace of speech indicated some degree of anxiety. At this point, she was observed to put her head down and begin flicking through the photographs, which was understood by me as indicating that she no longer wished to speak about a subject which may have been anxiety provoking.

Consequently, it seemed that the young people in this study were keen to present a preferred identity that CF did not impact on them emotionally, and as the researcher, I was happy to let them. It is possible that this was an accurate reflection of their lives with CF, and one which would be in keeping with empirical studies which have shown that young people with CF differ little from their peers in the likelihood of experiencing anxiety and depression (Anderson, Flume, & Hardy, 2001;

³² As discussed in section 4.4 this may have been in part been due to conflict between my role as (trainee) therapist and that of researcher.

Besier & Goldbeck, 2011; Blair, et al., 1994; Bregnballe et al., 2007; Goldbeck & Schmitz, 2001; Havermans et al., 2008; Pfeffer et al., 2003; Szyndler et al., 2005). However, maintaining this position might have served an adaptive function, both for them and those around them, by allowing them to further engage in talk that reinforced this preferred identity (i.e. talk of being a normal teenager rather than talk of their difficulties) and reassuring those around them that everything was ok. Indeed, following my interviews with many of the young people I was struck by how well they appeared to be coping, only on analysis did I begin to feel that this image was incongruous with some aspects of the way the stories were told.

Evidence suggests that where there is no chance of recovery, people with chronic illness may be more inclined than those with a positive prognosis to mask emotional difficulties (Charmaz, 1983). There are several possible reasons for this. Firstly, they may feel there are limits to the support available to them from others and so they avoid complaining about their illness to reduce the likelihood that others might see them as a burden (Atkin & Ahmad, 2001; Charmaz, 1983). However it might also be an attempt to establish a normal life for the self by moving the focus away from their illness and focussing on living a life despite chronic illness (Badlan, 2006; Charmaz, 1991; Conrad, 1987; Taylor, Gibson & Franck, 2008). For young people with chronic illness, who are more likely than their healthy peers to experience others as over-protective (Atkin & Ahmad, 2001; Gallo, Schultz, & Breitmeyer, 1992), providing reassurance to others that they are ok may also reduce the limitations imposed on them (Kyngas & Barlow, 1995).

While putting on a 'brave face' may be adaptive for the young people in this study, could this make it difficult for them to acknowledge and access help if it is needed? Williams et al. (2009) noted that young people and their parents often had a mutual desire to protect each other from emotional consequences of CF which might inadvertently prevent a supportive sharing of fears between the young person and their family. Similarly, while health professionals recognise the importance of allowing patients space to talk, systemic pressures may mean that the opportunity for this is reduced (Varcoe, Rodney, & McCormick, 2003). However, these interactions may be driven by broader societal narratives which perceive CF as a tragedy rather than opportunity for growth or a process of discovery (Charmaz, 1995; McDonough, 1998). These narratives may be understood through consideration of the historical context of CF in which to be diagnosed with this illness would have been a tragedy for the young person and their family, and opportunities for development may not have been considered relevant. However, with the improving prognosis for young people with CF, it is more important to consider possibilities for growth and development. This may be relevant for

clinical practice, highlighting a need to provide a space for young people with CF to talk about their emotional experiences, and acknowledging that young people and those around them may benefit from being made aware of alternative constructions of chronic illness.

Being a Normal Teenager; Maintaining a Preferred Identity Through their Relationships with Others

While participants spoke of CF as *“just a part of life”* (Amy), they were aware of what was normal for peers, and through their narratives attempted to align themselves with this norm. One way in which participants were seen to do this was through disidentification (for review, see Ellemers, Spears, & Doosje, 2002) with others with CF and resisting narratives of ‘illness’. For example, Sara noted that she was *“able to do stuff that other CF-ers...they just can’t”*. Similarly when talking of someone else at school with CF Claudia said *“we’re both completely different”*. Claudia followed this with a story of how she was like her healthy peers, presenting a preferred identity of being part of the norm. This finding conflicts with earlier research which found that in middle adolescence, young people with CF were likely to align themselves with others with CF in order to attain a sense of group membership (Christian & D’Auria, 1997). The reduced opportunity for young people to interact with others with CF may mean that this is no longer the case, and go some way to account for these disparate findings. However, it is worth noting that Miranda described how *“it helps if you know that there’s more people (with CF) [...] coz then you’re not left out”*. This might suggest that for some young people, an awareness of others with CF may play a role in how they make sense of their illness, providing them with a sense of belonging which is important for the development of a positive self image (Bat-Chava, 1994; Rowley, Sellers, Chavous, & Smith 1998). Nevertheless, as will become apparent, the majority of participants in this study appeared to gain this sense of belonging through aligning themselves with their healthy peers.

Participants drew heavily on cultural narratives of what it was to be a ‘normal teenager’, positioning themselves within this narrative through the way they described their attitudes (e.g. sharing a dislike of school and homework with peers), and aligning themselves with peers and away from authority figures such as teachers by mocking them. Moreover, the language used frequently contained terms recognised to be part of the adolescent register including non-standard discourse markers such as “like” (Erman, 2001; Siegel, 2002) and slang terms such as *“chill-axed”* and *“random”* which denoted membership to the teenage population (Gee, Allen, & Clinton, 2001; Nippold, 1993).

When asked *“how would you describe yourself”* many of the participants answered by comparing themselves to peers. On describing herself as *“crazy”* Miranda contextualised this by saying she would *“sort of come up with really random ideas (.) but so does Frankie and Kara (.) coz they’re really crazy too”*. This worked to convey a preferred identity of being like her friends. This was also communicated in participants’ stories of the activities in which they engaged. Both Rob and Amy (the eldest in the sample) spoke of drinking alcohol with peers. Rob talked about this as a means to *“chill”* with friends, whilst Amy talked of getting drunk with friends at her birthday party. Both appeared relaxed as they spoke about their experiences, portraying this as part of their norm. Nevertheless for Amy, who also had CF related diabetes, the statement *“I don’t really think about it I just (.) think about it in the morning (.) and then sort it all out then”* demonstrated an awareness of her difference from peers as she attempted to reconcile her preferred identity of being able to do what her peers do, with that of being mindful of her health.

All participants talked of engaging in sporting activities and of performing as well as, or better than peers. Miranda spoke about her performance in races at a local running club, reporting how she *“came near the other girls in the school”* thus positioning herself as performing at a level similar to that of peers. Moreover, in Amy’s story of being a gymnast, she talked about having been at her *“peak”* before leaving, portraying an image of herself as outperforming her peers. Consistent with earlier research therefore, engaging in ‘normal activities’ seemed to reinforce a sense of non-difference for these young people (Angst, 2001).

Some participants did however acknowledge ways in which they differed from their peers. In some instances, this was portrayed as a choice and a preferred part of their identity (e.g. Miranda, see global impression). However, at other times this was linked to what they perceived as their limitations. For example, when talking about her relationships with friends, Claudia noted *“I can get annoying (laughs)”; I’ll try and give them advice (.) but it would probably be like rubbish (laughs)”*. As noted previously (talk of her memory) and as seen here, Claudia surrounded her talk of her idiosyncrasies with laughter. This was seen in many of the other accounts. In his story of being shorter than his peers, Rob noted how:

Rob: *[...] they’re like “oh didn’t see you down there” I’m like “well I can’t see your face (.) I have to look up” (.) banter (.) pretty funny (laughs)*

In this way, Rob couched his story of being different from peers in humour, which he spoke of doing with his peers through reference to 'banter'. Thus it may be that humour or banter had an adaptive function, allowing them to acknowledge yet distance themselves from their differences from peers, and present a positive sense of self (Lefcourt, 2001). This is consistent with the view of humour as a discursive tool used to construct a situated sense of social identity (Holmes & Marra, 2002).

Through their stories of being normal, the young people appeared to be working to present a preferred identity of the self as the same as their healthy peers, and as able to do "*whatever else they're doing*" (Rob). This may be adaptive, preserving their self-esteem. Indeed, the literature highlights how young people with chronic illness may find it difficult to perceive themselves as different from their peers (O'Dougherty & Brown, 1990). Indeed, during adolescence, self-other comparisons have a marked influence upon the developing self-image and self-esteem (Hetherington & Parke, 1993). Thus, to perceive themselves as different may negatively impact upon the young person's developing sense of self. However, it emerged through their stories that positioning themselves as normal teenagers not only served to protect their developing sense of self, but maintained their preferred identity in their relationships.

There was a sense, both from the content and performance of their stories that the young people did not want others to perceive them as different. For example, Amy told a story of her teacher making CF "*a big deal*" when she and her friends were dunking each other in the pool during a swimming lesson:

Amy: *[...] and we were all like dunking each other (smiling and gestures pushing down as if pushing someone under water) she's like (teacher) (.) "no no no don't do that" and I was like "why?" (.) and she's like "coz your lungs are really bad you can't stay under water" (.) and I was like "yeah I can" (exasperated tone [...])*

Through this story Amy communicated an attempt to show others that her CF did not make her any different from peers. The example chosen (being dunked) is interesting as it is something that some find unpleasant. Though she portrays herself as having enjoyed this game, in attempting to be perceived as 'normal', would it have been possible for Amy to say otherwise? In Daniel's story of the games he played at school, he presented a similar scenario when he spoke of playing 'Sting ball', a game in which they 'lob' tennis balls at each other's legs in order to catch them out:

RA: [...] *that's got to hurt a little bit*

Dan: Yes (.) *especially when it's been wet (.) and when you're cold (.) it stings more (smiles)*

RA: *Who comes up with these games?*

Dan: *Hmm...oh...well (3) everybody sort of [...]*

In acknowledging that 'everybody' plays these games it could be argued that like Amy, Daniel engaged in this game to be perceived as 'normal' by his peers. However, in choosing to tell this story and through the way it was performed, he appeared keen to communicate to me, or his peers as a ghostly audience, that he was able to tolerate the pain involved in playing this game. Research suggests that the perspectives of peers are crucial for social acceptance and that similarities among peers denote group membership (Coie, Dodge, & Kupersmidt, 1992; Hartup, 1993; Parker, Rubin, Price, & DeRosier, 1995). For young males, physical prowess is also important for social acceptance, and many young males engage in rough play to promote their social status (Boulton, 1992). For Daniel, as a young person with CF (and who described being shorter than many of his peers) it is likely that playing games like sting ball form an important function in relating to others and asserting an image of himself as equal to his peers.

It is worth noting that alongside efforts to be perceived as normal in order to facilitate positive relationships with peers and maintain a preferred identity, some participants spoke of their interactions with family members and specifically, wanting to be normal for the sake of others. For example, Miranda described how her brother was unable to have one of his friends over because she had CF, and acknowledged how "*he [her brother] finds it quite hard because erm (.) he...he can never have Luke around*". During this story, Miranda had her head down and appeared guilty that it was because of her that her brother could not have his friend over. Similarly, Amy described how her sister complained "*well everything's about Amy isn't it?*" and talked of feeling "*quite mean because I admit...most of the time (.) mum is concentrating on me coz of everything*". Amy presented herself as regretful of the impact her illnesses had on her sister's life and noted that she was taking steps to be more responsible for her medication so that she was no longer the focus of her mum's attention.

Both Amy and Miranda appeared to be acknowledging the difficulties faced by siblings of those with a chronic condition such as CF. While there are a number of studies concerned with how siblings feel (Eiser, 1993; Foster et al., 2001; Walker, Garber, & VanSlyke, 1995), to my knowledge this is the first

study to show how this impacts on the young person, and highlights how they may experience feelings of guilt or remorse in regard to this. Like Amy, these feelings may prompt the young person to make greater effort to allow their sibling the opportunity for attention from parents. Though it is not apparent from these stories, it may be interesting to consider whether this may add to the feelings of not being able to complain, leading them to minimise their difficulties.

While this section has explored how participants positioned themselves relative to others in their stories of being normal, it is noteworthy that across the sample, there were differences in how the participants peopled their stories. These differences were for the large part defined by the age and sex of the participants. Thus, the girls produced accounts in which they were surrounded by others while the boys seemed to reference others less frequently, and more in relation to particular activities or events in their lives. For example, Daniel's story of the important people in his life rooted his interactions with friends in the activity of playing computer games as he described how his main friends were *"Uhh people called Jack and Will (.) we're all on PS3 (PlayStation 3)"*. By contrast, Claudia told stories not only about what she did with others, but also the nature of her relationships, for example describing the reciprocal nature of her friendships, *"I know that they look out for me [...] so I look out for them"* and the work engaged in to maintain her relationships, *"so I bought her some [pink jelly] and said 'let's make peace' "*.

Furthermore, while Amy and Rob, the eldest in the sample spoke more of their relationships with friends, there seemed to be a greater balance of stories of friends and family in the accounts of Miranda, Claudia, and Daniel which might have been indicative of their stage of development. As noted previously, Sara's account varied greatly from that of other participants containing few stories of friends. Sara accounted for this as owing to the fact that she had not been to school since moving to the area, limiting her opportunities to build peer relationships. Nevertheless, there was also little mention of friends in her childhood stories. While her frequent hospital admissions as a child might have made it difficult for her to maintain peer relationships, more than the other young people she spoke of being close to extended family members. Therefore, this may reflect a cultural difference in the importance placed on friends and family (Höllinger & Haller, 1990).

These findings largely reflect what is known of the changing value of family and peer relationships over the course of adolescence (Gecas & Seff, 1990), and the propensity for girls to be more heavily invested in their social identity than boys of this age group (Gilligan, 1982; Hodgson, & Fischer, 1979; Josselson, 1973; Josselson, Greenberger, & McConochie, 1977; Patterson, Sochting, & Marcia, 1992). Nevertheless, given the role played by others in how young people in this study made sense of their

CF, it may be important to hold these differences in mind when thinking about the way in which young people may be supported during this formative period.

3.3.3 Storylines of the Future

In response to being asked where they saw themselves in the future, all young people told stories about the future though there was variation in how much emphasis they placed on this, ranging from Claudia, who stated “*I don't really think about it that much [...] I just like (2) focus on now*” through to Miranda who presented a detailed account of her hopes and fears for the future. Nevertheless, with the exception of talk about being more independent (which for all included taking greater responsibility for their treatment), talk of the future was embedded within broader narratives of what was normal: to go on to University, spend greater time with friends, gain employment and for some, to start a family. Thus talk of being part of the norm also dominated their stories of their future selves. Indeed, only a few of the young people told stories about a future with CF and seemed willing to acknowledge the difficulties that might lie ahead.

This finding is consistent with contemporary research which found that young adolescents with CF talked of having a career, travelling, and having their own family (Jessup & Parkinson, 2010; Lannon Palmer & Boisen, 2002), and may reflect advances in the treatment of CF. Indeed, that these young people are able to share many of the aspirations of their peers is a stark contrast to what would have been the picture forty years ago, when becoming a teenager would have been the ambition of children with CF (Tropauer, Neal Franz, & Dilgard, 1970). Nevertheless, it may also reflect the sense of invincibility that is often held by teenagers (Brink, Miller & Moltz, 2002; Johnson, 1988), which though largely protective, has been shown to impact on things such as adherence to treatment in young people with other chronic conditions (Brink et al., 2002).

Increased Independence and Transition

Transition towards greater independence from parents emerged in many of the participants' narratives. This involved taking greater responsibility for medication, and having more freedom from parents. Concerning the former, most spoke of being at least partly responsible for the management of their treatment and of having been the ones to take greater control over their medication. Rob described how:

Rob: [...] I got annoyed they [parents] were always sitting with me (.) I was like “I can do it [treatment] myself” (.) so I was like (.) “I’m doing it myself”

Thus for Rob, frustration at having his parents supporting him with medication led him to take it upon himself to do his treatment alone. Though not at the same stage in managing her medication as Rob, Sara spoke of how “I prefer to take them [pills] in my own time rather than actually when I’m told to” indicating a desire to shift away from parental control over medication to taking greater responsibility for her treatment. This finding is consistent with that of an earlier study (Foster, Bryon, & Eiser, 1998) that found that for young people with CF, adolescence is punctuated by a move towards independence from parents in the management of treatment, a process which may be tumultuous as the young person’s desire for independence conflicts with the parental need to protect them.

Nevertheless, some participants noted that taking responsibility for their treatment was something they were not ready to do. Claudia remarked that “I know how to do all my own medication (.) but my mum still helps”, indicating that she was content to have support from her mother, though she noted that she expected to take more responsibility over the coming years. While Amy was further along in the process of managing her medication, she too described how her mother continued to support her with treatment, talking about her counting out Amy’s pills. Though Amy talked of taking steps towards managing her own medication³³ there appeared to be some apprehension as she noted that “in the morning I just don’t know (.) my brain doesn’t work properly (.) so I think I’d probably get it more wrong”.

For all participants, the transition towards greater independence was not only signified by greater responsibility, but also greater freedom, as they spoke of a life without being told what to do by parents. Daniel spoke of how without “mum nagging me” he could “do what I want (.) have freedom” which he talked of as meaning he would be able to spend more time on his PlayStation. By comparison, Claudia noted that “I’ll probably spend more time with my friends”, which she elaborated on using the example of going to Centre Parcs with friends in the school holidays.

Through their stories, these young people demonstrated how for them, a move towards independence from parents was seen as an achievable developmental task of adolescence. Like their healthy peers, transition and increasing independence included taking on greater responsibility and attaining greater freedom from parents. Perceived in this way, this may bring with it many of the challenges normally associated with adolescence, as the young person strives for greater

³³ As discussed previously in reference to the impact on her sibling

independence from parents (Frydenberg, 1997; Midence & Elander, 1994). However, research suggests that disagreements over treatment and the young person taking greater responsibility for their own treatment may be linked to a reduction in adherence (Butner et al., 2009). Consequently, some families may benefit from additional support through this period, to manage the challenges that transition may bring.

A Future with CF

While there was talk of the future across the narratives³⁴, how CF might impact on this was often an afterthought, spoken about in relation to educational or life goals. Amy's infection and subsequent hospital admission around the time of the interview perhaps heightened her awareness of how CF might impact on her future, as she talked about how she might struggle to achieve the grades she needed to get into college. Nevertheless, beyond this, she was more concerned with how her academic difficulties³⁵ might impact on her future, stating *"I'm scared I'm not gonna get a good job (.) just because I'm not very academic"*. Similarly, Rob spoke of how CF might impact on his preferred career as a footballer, noting *"I'd like to but (.) don't think I'll be fit enough [...] maybe CF (.) maybe it'll kick in later (.) and that'll stop me"* but saw himself going on to University and living independently, which he spoke about without any reference to how CF might impact on this.

While Rob and Amy acknowledged some of the difficulties they might face in the future they talked of not thinking *"that far into the future"* (Rob) and that they were *"not gonna think over-think it"* (Amy). This was consistent with the amount of time given over to stories of the future in their accounts, which was minimal when contrasted with the amount of talk about the present. Stating they did not think about the future may have been an attempt to present an identity that was congruent with talk of CF not being central to their lives in the here-and-now. However, it might also be that living in the present was a learned response to the unpredictable nature of CF.

In contrast to Rob and Amy, Miranda spoke about her fear that CF might lead her to die young. She noted:

Miranda: [...] you hear like (.) there's this singer called (XXX) or something like that (.) and Robbie Williams helped her but she dies coz (.) she needed a lung transplant and she didn't get one (.) and so sometimes that worries me a lot...

³⁴ With the exception of Claudia as noted previously

³⁵ Amy talked in her account of having been diagnosed with dyslexia and dyscalculia

Interestingly, this talk did not emerge until very near the end of her narrative, suggesting that this was not something she wished to talk about. By contrast, she spoke at length of being worried about how not getting good grades, and how the current economic crisis might impact on her future, summing up her story by saying:

Miranda: well if you don't get an A then you're sort of (.) doomed sort of (.) you...you're not gonna get a good job and you're not gonna (.) get paid and the amount houses are (.) that worries me because the amount money's going down [...] it's just worrying when you don't know what's going to come when you get older...*

The contrast between the amount of time given to talking about worries about grades and the economic crisis versus CF might indicate that while she was able to reconcile future worries about CF within her portrayal of self, CF may have been less of a concern to her at the time of the interview. Alternatively, it might have been easier for Miranda to talk about being worried by events that were distant from her, than to talk about CF, of which her daily treatment regimen would have been a constant reminder (Jessup & Parkinson, 2010). Moreover, as her concerns about the economy were likely to be shared by the general population, this served to position her concern as a 'normal' reaction to societal events.

For these participants, their talk of the future suggested that the potential impact of CF received little consideration, though there was an awareness that CF might impose some restrictions on their future selves. Some spoke about this as related to their preference to focus on the present rather than to try to anticipate what might occur for them in the future. This may actually be construed as adaptive when coping with an unpredictable illness such as CF, where there may be a need to continually revise thoughts of the future (Williams et al., 2009). Indeed, this idea underpins approaches such as Acceptance and Commitment therapy and Mindfulness (Hayes, Luoma, Bond, Masuda, & Lillis, 2006), which have a good evidence base as psychological interventions for individuals with chronic illness (Feinstein et al., 2011; Wallace, Harbeck-Weber, Whiteside, & Harrison, 2011) Thus through their experiences these young people may have adopted this approach to manage the worry that might otherwise be caused by trying to predict and control what their life with CF will look like.

This study sought to hear the stories of young people with Cystic Fibrosis (CF): what it was like to be a young person with CF, and how they reconciled their illness experiences within their developing sense of self. In this chapter, I will provide a discussion as to the clinical relevance of the study findings and the potential implications for service delivery. I will then consider the strengths and limitations of this study, and potential areas for further research, before ending with a summary of my personal reflections on the process. I will begin by providing a summary of the main findings of the study in relation to the specific research questions put forward to explore how young people with CF make sense of their illness in narrative.

4.1 SUMMARY OF FINDINGS

4.1.1 How do young peoples' narratives describe and account for their relationship with CF over time?

This study found that these young people talked about their experiences of CF over time as being a continuation of what was “normal to me”, which may have been fostered by their interactions with family members. Williams et al. (2009) noted that what is identified as normal for young people with CF may be defined by their earlier experiences of illness and treatment and the way in which this was talked about within the family. Based on their findings, Williams, and colleagues, hypothesised that there may be a shift as the young person enters adolescence, from self-to-self comparisons to self-to-other comparisons that may bring a realisation of difference. Indeed, the reflective account of an adult with CF highlights how *“The memories I have as a child might seem quite strange to some people, for I always had this feeling that I was something special. I was almost proud to tell friends I had an illness, never ashamed or embarrassed. That came later”* (Peek, 2001). Nevertheless, some of the young people in this study talked of being aware that they were different from others as children. Moreover, how they understood their illness was described as having been shaped by their interactions with others as their experiences of illness appeared to have been normalised and defined by their families. Thus, rather than there being a ‘shift’ from a reference system based on the self to one based on the other, from a very early age children begin to make sense of their illness experiences and construct a sense of self through their interactions with others (Miller et al., 1990).

What may 'shift' therefore, may be the people in these interactions as the young person progresses from a world in which family is most influential, to a world where peers receive precedence.

Participants' talk of continuity over time contrasts with the ideas of biographical disruption (Bury, 1982) and loss of self (Charmaz, 1983) said to occur with the onset of chronic illness in adults, where onset denote a disturbance of the person's view of the self, body, and society. Consequently, this study demonstrates how young peoples' illness experience may differ significantly from that of adults, particularly if they have lived with and been diagnosed with the condition from a very young age, and highlights the importance of exploring the illness narratives of children.

4.1.2 What aspects of the self are expressed in these narratives? How do the young people position themselves relative to themselves, others, and the broader societal narratives available to them?

The participants' constructing CF as normal to the self, and as something that they did not think about much, allowed them to separate out who they wanted to be from the behaviours and practicalities of being a young person with CF, allowing them to position themselves as similar to their healthy peers and as part of the norm. This finding is consistent with previous research which showed that young people with CF aligned themselves with healthy peers (Badlan, 2006; Williams et al., 2009). The young people in this study drew heavily on cultural narratives of what it meant to be a normal teenager, applying these to themselves both in their talk of the here-and-now and in their stories of their hopes and fears for the future. There was a sense that this identity served an adaptive functioning, allowing them to foster relationships with peers, through which they might develop a positive self image (Hetherington & Parke, 1993). Nevertheless, through the performance of their narratives, the young people adopted a position from which there was a tendency to minimise difference and thus, difficulties and distress that might be attributed to CF. Indeed, while participants acknowledged previous feelings of fear, frustration, and anxiety in relation to their CF, most seemed less willing to acknowledge that CF impacted on their lives in the present, talking only of feelings of annoyance and reporting that it was not a big thing. This finding may have important clinical implications, which are discussed in more detail below.

4.2 CLINICAL RELEVANCE OF FINDINGS AND IMPLICATIONS FOR SERVICE PROVISION

4.2.1 Therapeutic alliance and providing the young person with a safe space to talk

Within this study, the interactions between the participants and researcher allowed the young people to maintain a preferred identity that CF had little impact on their lives and that they were similar to their healthy peers. While this might serve an adaptive function, fostering the development of favourable self-other comparisons, there may be times when young people find it difficult to maintain this preferred identity owing to exacerbation of symptoms or an awareness of the impact of CF on their life (Wilson, Bladin, & Saling, 2001). At these times, healthcare practitioners may play a key role in supporting the young person to manage threats to the preferred self (McDougal, 2007). Nevertheless, as NICE prioritise the physical health needs of young people with CF, many services operate without the support of professionals such as clinical psychologists who are ideally placed to provide such support. Where psychological support is available, this study suggests that by taking the stance that they are able to cope, young people may find it difficult to admit they need help. This may be compounded by stigmatised beliefs that society hold concerning what it means to access psychological services (Deane & Todd, 1996; Kelly & Achter, 1995). Therefore, there is a need for services to work with young people and their families to ensure that psychological support is perceived as a normal and valuable component of the young person's treatment. This may be aided by regular contact with a clinical psychologist at routine and annual review appointments, as recommended by the CF Trust (Cystic Fibrosis Trust, 2011).

4.2.2 Considering the person holistically

Following on from the above and consistent with guidance from the CF Trust (Cystic Fibrosis Trust, 2011) the findings from this research would advocate the use of a person-centred, holistic approach to care, taking into consideration the young person's physical health, their psychological wellbeing and the biopsychosocial factors that might influence this. This may include consideration of how the beliefs of the young person's family, peers, and society might influence how the young person with CF makes sense of their illness experiences. Moreover factors such as the young person's gender and developmental stage bear consideration as these may also play a role in how the young person makes sense of CF. Consequently, this would suggest that clinicians should employ an approach to the assessment, formulation, and intervention that allows them to incorporate these factors in their attempts to understand the young person's experience.

4.2.4 Consideration of Systems

Further to the above, the study findings highlight how the narratives of parents, peers, and society were all found to play a role in participants' co-constructions of what it was to be a young person with CF, and how and why they chose to perform their preferred identity. Moreover, some of the young people talked of the impact CF had on their siblings, highlighting that those around the young person may benefit from support. Thus, it may be beneficial for services to consider the wider system, and consider interventions that might address the impact CF may have on others, enabling those around the young person with CF to provide them with adequate support.

One area which was highlighted by the study findings concerned the child's family. Indeed, for many of the participants, the perspective that CF was a normal part of life was nurtured by their interactions with family members. It may be beneficial therefore, for families to be made aware of the potential benefits of integrating CF into their narratives of what is normal for the family. At present, many services provide support for parents following the diagnosis of CF in their child. This varies from psychoeducational leaflets, to support and psychoeducational groups and in some cases one-to-one psychological support (based on information retrieved from the Paediatric Psychology Network, May, 2012). Nevertheless, the focus of such interventions appears to be on the implications of CF for the child's physical health, managing treatment, and guidance on explaining CF to the child. Therefore, there may be scope to work with parents in these early stages, to think about how they may help the child develop a positive relationship with their CF, and come to view it as a normal and acceptable part of their life.

The study findings also suggest that peer understanding and acceptance of CF may be linked to the young person's acceptance of CF in later childhood and adolescence. Consequently, it may be beneficial for services to provide interventions within schools, to help others understand CF and its implications for the young person and those around them. Studies have shown that failing to disclose a diagnosis of CF may be associated with negative peer perceptions (Berlin, Sass, Davies, Jandrisevits, & Hains, 2005). Moreover, as previously noted, the literature freely available regarding CF tends to focus on what the young person finds difficult, which may mean that without proper information, those around the young person may inadvertently impose unnecessary limitations in their attempts to look after them. Thus, clear psychoeducational interventions may help those around the young person to better understand their needs and allay any anxieties they might have.

Thinking more broadly, one of the major findings in this study was the importance ascribed by these young people to being seen as part of the norm. Through consideration of how broader narratives influence the young person's co-construction of their narrative, it is possible to see that this may be influenced by society's inability to accommodate difference (Atkin & Ahmad, 2001; Barnes, Mercer, & Shakespeare, 1999; Oliver, 1996). This idea has received much interest in relation to topics such as mental health and disability, with several initiatives developed to reduce the stigma associated with these areas. These highlight the importance of creating an atmosphere of openness and hearing patients' stories in order to dispel the misconceptions that might arise, and challenge negative beliefs (Pinfold, Thornicroft, Huxley, & Farmer, 2005). Though predominantly aimed at adults, a growing number of initiatives work with children, particularly in settings such as schools and youth clubs. Though the evidence base for such initiatives remains limited, that which exists suggests that these may be effective in reducing negative stereotypes associated with difference (Corrigan & Gelb, 2006; Pinfold et al., 2005). While arguably the social disability model may apply to young people with CF (for definition see Oliver, 1996), more may need to be done to challenge the stigma associated with chronic illness as a source of difference in childhood and adolescence. Service users, health care professionals, and registered charities may all be in a position to engage in this work.

4.3 METHODOLOGICAL CONSIDERATIONS

4.3.1 Strengths

A strength of this study was that it was innovative and explored the experiences of adolescents with CF which has been largely under-represented in the literature. Consequently, it contributes to our understanding of an important area of human experience and may inform service provision, helping us to understand how to support young people with CF as they traverse adolescence. Furthermore in adopting a narrative approach which focuses upon the psychological and social processes involved in meaning making (Weatherhead, 2011), it allowed for counter-narratives to dominant discourses to be considered, providing young people, their families and health professionals with alternative narratives to the dominant narratives which are largely concerned with the medical and physical aspects of CF, and emphasise limitations that the young person may experience.

Arguably a further strength is the use of photo elicitation methods. Using this approach has been shown to help young people to engage in the research process (Buckingham, 2009; Drew et al., 2010). Moreover, as noted by Clark (2003) employing photo elicitation may overcome some of the problems associated with interviewing children, by giving young people greater control over the

research process, addressing power asymmetries in the research relationship, and serving “as a protection for these young informants, since the children maintained control of whether and when to mention vulnerable topics” (Clark, 2003, p.157). Nevertheless, while using this approach may to some extent empower the young person, it is important to hold in mind the institutional hierarchies that may continue to influence narrative co-construction (Buckingham, 2009; Kaplan & Howes, 2004)

4.3.2 Limitations

There were several limitations to this study. Firstly, while arguably a strength, using photograph elicitation brought with it a number of challenges. As noted previously, the young people’s stories tended to stay close to the content of the photo. Thus, using the photos may have restricted their narratives to their day-to-day experiences, making it difficult for them to introduce narratives of the past and future (Robinson, 2002). Moreover, there was variance in how much parents guided the process and thus their narratives, with two participants noting that their parents had suggested they take particular photos. Nevertheless, the epistemological position adopted in this study permitted consideration of how these processes influenced the stories told. Furthermore, all the interviews allowed participants to talk for periods without reference to the photos, giving space to consider storylines that photo elicitation alone may not have afforded.

A further limitation of this study may be the method by which data was collected, i.e. a single, lightly structured interview. Owing to the time constraints imposed on this investigation, it was not possible to undertake multiple interviews. However, Williams and colleagues (2009) highlight how such an approach might allow the development of a more trusting and open relationship which might facilitate the co-construction of more personal narratives. Thus, conducting multiple interviews may have enabled further exploration of some of the inconsistencies that emerged in the participants’ narratives, allowing a more in-depth understanding of the way the young people made sense of their illness experiences over time. Moreover, the use of a cross-sectional rather than longitudinal design might not have captured participants’ experiences of the variability of symptom severity associated with CF, which might arguably have implications for their perceptions of CF and notions of normalcy. Thus, future research in this area may benefit from employing a longitudinal design to allow the researcher to explore changes and developments in the narratives over time.

Not only may the use of only one interview be subject to criticism, but the use of an interview at all. A number of researchers have highlighted the potential limitations afforded by this method of data collection (for discussion see Miczo, 2003). Particularly relevant here are the ideas that interviews do

not provide “naturally occurring data” (Schegloff, 1997), and the tendency for what is said to be taken at face value (Sandelowski, 2002). Concerning the former, it may be argued that the interview has become as widespread as any other form of interaction within Western Society (Atkinson & Silverman, 1997) and therefore has its own conventions which are known to participants (Shakespeare, 1998). Moreover, if we take the position that narrative co-construction provides the individual with a situated opportunity to build upon previous telling of the self, then the narratives co-constructed in interview may be analysed as part of the ongoing identity work of the participant (Taylor & Littleton, 2005), making it particularly useful within the context of this study.

Regarding the latter, adopting a social constructionist approach allowed consideration of not only what was said, but also what might have been the purpose of performing the narratives in such a way, and how the narratives may have been shaped by local and broader contextual factors. Thus, rather than succumbing to the “fetishism of words” (Miczo, 2003, p.469), effort was made to consider how the characteristics and motivations of the participants and researcher shaped the co-construction of the narrative.

Finally, it is important to acknowledge how my limitations as a researcher may have impacted upon the co-construction of the narratives. Indeed, Johnson and Clarke (2003) note that researchers from clinical backgrounds may find that the skills and way of thinking that they have learned to apply in the therapeutic setting conflict with the role of researcher. This was something that I feel I struggled with when conducting the interviews. Moreover, the process of data analysis might also have been influenced by my position as a therapist owing to a tendency to look for problems (Sharry, Madden, & Darmody, 2012). In an effort to prevent this I endeavoured to stay close to the data.

4.3.3 Suggestions for Further Research

It was appropriate to employ only a small number of participants within this study to allow a rich analysis of the data (Wells, 2011). Nevertheless, our understanding of the experiences of young people with CF may be furthered through repetition of this study with a larger sample. Moreover, while this interview allowed the researcher to elicit information about a variety of topics relevant to the young person, future research might be necessary to gain a more in-depth understanding of particular aspects of experience. This may incorporate photo elicitation methods that specifically ask participants to include pictures of their past, or to represent their hopes for the future, in order to overcome some of the limitations of using this approach.

A major finding of this study concerned how those around the participants helped them to accept CF and feel part of the norm. Therefore, it may be interesting for future research to consider the stories told by those around young people with CF: how they make sense of the illness and how this is informed by wider narratives about chronic illness and CF specifically. While a number of studies have explored the perceptions of family members (e.g. Blair et al., 1994; Foster et al., 2001; Thompson, Gustafson, Hamlett, & Spock, 1992; Williams, Mukhopadhyay, Dowell & Coyle, 2007), these have typically been concerned with how family members beliefs and behaviours might inform the young person's perception of CF, familial psychological wellbeing, and treatment management. Future research could explore the factors that influence parental understanding of CF, and how this might influence how young people make sense of their experiences. Moreover, to date there is only one study that has considered peer attitudes towards CF which was concerned with how peers who were unaware of the health status of the young person might interpret their bodily appearance and treatment (Berlin, et al., 2005). It may therefore be helpful for future research to consider the beliefs held by the peers of those with CF: to consider how these beliefs are formed and whether more may be done to support the development of positive beliefs about the illness.

4.4 PERSONAL REFLECTIONS

Within qualitative research it is important to consider how the self of the researcher may influence the research process (Emerson & Frosh, 2004). However, having undertaken this piece of research I feel it is also important to recognise the impact of the research on the researcher. Consequently, I felt that the process of obtaining data and employing narrative analysis (NA), where the link between the research and the researcher was most strongly felt, warranted discussion in the final section of this chapter³⁶.

Firstly, concerning the interviews, I feel I approached the initial interviews rather naively, anticipating that as the young people had volunteered to participate they would be willing to talk about their experiences of living with CF. However, what I found was that when given the opportunity to tell their stories, CF did not emerge strongly in their stories. Consequently I struggled to know whether I should ask questions about CF or allow their stories to unfold. While I tended to lean towards the latter, only asking about CF when they brought it into the conversation, I acknowledge that on some level this might have influenced the co-construction of the narratives.

³⁶ While I acknowledge that obtaining ethical approval for the study also impacted upon me personally, I believe this is discussed in sufficient detail in the method section and therefore this will not be discussed here.

My usual position as a (trainee) therapist may have conflicted with my role as a researcher, influencing the interview process. Like many who hold the dual roles of therapist and researcher (Dickson-Swift, James, Kippen, & Liamputtong, 2006; Johnson & Clarke, 2003), while I felt drawn to explore the difficulties the young people may have faced, I was concerned about opening up difficult discussion given that they may not have a protected space in which to discuss issues highlighted by the interview³⁷. Consequently, I found myself offering reassurance to participants at times, and not pursuing issues that appeared distressing to them. Nevertheless, as interviewing continued I became more confident in my ability to ask about difficult subjects, as the young people who told stories of adversity reported that they had found it helpful to talk about these experiences. This is in keeping with research that has shown that participants may find research interviews therapeutic, as like therapeutic interviews, they provide a space for the person to talk about their experiences to someone who wants to listen (Duncombe & Jessop, 2002; Hutchinson & Wilson, 1994).

The decision to employ NA in this research also had a significant personal impact. Through my reading I came to appreciate the benefits of using this approach for the purpose of this study. However, my previous research experience was limited to quantitative methodology and I therefore found adopting a qualitative approach, particularly one in which there was no 'one set way' to interpret the data (Riessman, 1993), hugely anxiety provoking. Nevertheless, during the research process, anxiety gave way to a sense of satisfaction as I was able to tailor the approach to the research aims. I found it immensely freeing to be able to attend not only to the content of what was said, but also the emotional and social nature of the stories helping me to gain an in-depth understanding of the participants' experiences of CF.

The process of conducting research with people with chronic illness can have a profound effect on the researcher (Dickson-Swift et al., 2006). This is true for me as the young people's stories led me to reflect on my own narratives of adolescence, and those of young people with chronic illness who I have worked with in my clinical practice. It has been an honour to bear witness to the stories of the young people who participated in this study, and I am thankful that they shared their stories, through which I have developed an understanding and respect for how these young people live their lives. I only hope that through this research we may share their stories with others with CF, their families, peers, and health professionals, to provide them with alternative narratives to facilitate their understanding of CF and inform service development.

³⁷ Though as discussed in the ethical considerations section, procedures were in place for the young people to be able to access a clinical psychologist after the interview should they feel this was necessary.

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APPENDICES

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APPENDIX A: LITERATURE REVIEW SEARCH STRATEGY

Stage 1: Initial Exploratory Search

An initial search began with a review of relevant books within the Learning Resource Centre at the University of Hertfordshire and database searches using Web of Science and Google Scholar. The search terms used at this stage were:

'Cystic Fibrosis' OR 'chronic illness' AND 'illness narrative'; narrative; adjustment; 'lived experience'; experience
'self image'; 'identity'
Adolescence; teen*; 'young people'

Stage 2: Following up references

From relevant articles, key references were identified and followed up. At this time, key authors were also identified and relevant papers obtained.

Stage 3: Contacting Researchers in the Field

From the list of key authors, several were contacted to obtain copies of papers that were not available through the University. In addition, I joined the Paediatric Psychology Network UK (PPN-UK) and liaised with Clinical Psychologists working in Cystic Fibrosis who were able to advise me regarding the nature of my research, the specific research question, and further references. Guidance in these areas was also provided by my supervisory team.

Finally, through the Local Research Ethics Committee board I was put in contact with a Clinical Nurse Specialist who had conducted research into the experiences of young people with CF, specifically in relation to the issue of treatment adherence. She was able to provide me with further references that might inform my research.

Stage 4: Detailed Review of the Literature over 18 months

Informed by my previous searches, I went on to conduct a detailed review of the literature according to the criteria outlined below:

Inclusion Criteria:

- Studies of young people with CF
- Papers published in English (or where translations were available)

- Peer reviewed Journals
- Papers which provided an insight into the experiences of young people with CF and/or emphasised the psychological processes involved in living with the illness rather than medical or treatment issues.

Exclusion Criteria:

- Studies of children with CF under the age of 10 years
- Studies of adults with CF

Dates of Search: 1985-2012

(It should be noted that while I was aware that advances in treatment and the ensuing increase in life expectancy for people with CF over the past 2 decades might render earlier research redundant, I felt it was useful to review some of the earlier literature to consider the changes that might be evident).

Search Terms

Using Boolean operators and truncation options to ensure all relevant papers were retrieved, the following search terms were employed:

- Cystic Fibrosis – CF, lung disorders, pancreatic insufficiency
- Adolescence– young people, teenagers, children, childhood, growing-up, adolescent
- Experience – lived experience, personal experience, journey, living with
- Adjustment – adaptation, coping, change, psychological adjustment, psychosocial adjustment, psychological affects psychological impact, psychological wellbeing, emotional adjustment, social adjustment, resilience
- Identity – self image, self concept, self perception
- Narrative – illness narrative, story, life story, biography, narrative reconstruction, biographical disruption
- Relationships – peers, parents, siblings, health professionals, interaction, friendships
- Qualitative Methodology – narrative analysis, narrative-discursive, discursive, social constructionism, qualitative methods, reviews, case study, case report, descriptive, meaning making, IPA, grounded theory, thematic analysis, phenomenology
- Photographs – photo voice, visual narratives, visual analysis, photo-assisted interviews, visual methods, photo-elicitation

Search Engines

Citation alerts were set up associated with key papers identified through the search. The following search engines were used:

- Web of Science
- Google Scholar
- Scopus
- Psyc Info
- Pubmed
- The Pro quest Theses & Theses database

General Web Searches

More generic sources were needed to inform certain aspects of the study. These were obtained through World Wide Web searches to locate the following:

- NICE guidance
- Department of Health guidance
- Cystic Fibrosis Trust
- Facebook
- National Research Ethics Service
- The Centre for Narrative Research

Ongoing Search of Specific Journals

The following journals were continually reviewed during the study to ensure that the most up-to-date research was referenced:

- Narrative Inquiry
- Qualitative Health Research
- Social Science and Medicine
- Narrative Research in Health and Illness
- Journal of Cystic Fibrosis
- Journal of Paediatric Psychology

APPENDIX B: LREC APPROVAL LETTER

NRES Committee East of England - Essex

East of Eng and Rec Office 1
Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Telephone: 01223 597633
Facsimile: 01223 597645

14 December 2011

Miss Rebecca Adlington
DClinPsy, Health Research Building
University of Hertfordshire, College Lane Campus
Hatfield, Herts.
AL10 9AB

Dear Miss Adlington

Study title: An exploration of the lived experiences of adolescents with Cystic Fibrosis (CF) and of their developing sense of self
REC reference: 11/EE/0231

Thank you for your letter received on 1st December 2011 responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair in consultation with the lead reviewers for your study.

Confirmation of ethical opinion

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

Ethical review of research sites

NHS sites

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

Non-NHS sites

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.r4forum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

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

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

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		
Evidence of insurance or indemnity	UMAL	01 August 2010
GP/Consultant Information Sheets	1	25 May 2011
Investigator CV	Dr Rebecca Adlington	01 May 2011
Letter from Sponsor	Professor J M Senior	25 May 2011
Letter of invitation to participant	1	25 May 2011
Other: project checklist		12 May 2011
Other: CV Wendy Solomons Supervisor		
Other: 11 EF 0231 valuation checklist 01.06.11		01 June 2011
Other: The Lives Experience of Adolescents with Cystic Fibrosis- Topic Guide	2.0	30 November 2011
Other: Guidance for obtaining photographs	2.0	30 November 2011
Other: Debriefing Information	2.0	30 November 2011
Other: Letter From Wendy Solomons		23 September 2011
Participant Consent Form: For Parents	2.0	30 November 2011
Participant Consent Form: Young Persons 16 years and over	2.0	30 November 2011
Participant Consent Form: Under 16's Assent Form	2.0	30 November 2011
Participant Information Sheet: 16 years and over	2.0	30 November 2011
Participant Information Sheet: Under 16's	2.0	30 November 2011
Participant Information Sheet: Young Person	2.0	30 November 2011
Protocol	2.0	30 November 2011
REC application	77032/21749 1/1/826	25 May 2011
Response to Request for Further Information		

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

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

Further information is available at National Research Ethics Service website > After Review

11/EE/0231

Please quote this number on all correspondence

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

Yours sincerely

Dr Alan Lamont
Chair

Email: suzanne.emerton@eoe.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Professor John Senior
University of Hertfordshire, College Lane Campus
Hatfield, Herts.
AL10 9AB

Wency Solomons
DClinPsy Health Research Building
University of Hertfordshire, College Lane Campus
Hatfield, Herts.
AL10 9AB

<p>Q15</p>	<p>Purpose of project and its academic rationale (preferably between 100 - 500 words):</p> <p>Many researchers have used a narrative approach to explore the unique and complex responses of individuals learning to live with chronic illness (e.g. Koch et al., 1999; Williams 1984). Underlying this, is the assumption that people make sense of their experiences through the stories they tell and that through consideration of these stories we may gain insight into the subjective experiences of living with chronic illness. Through this, healthcare providers may be better positioned to meet the psychological needs of the individual, which is an important factor in treatment adherence and medical outcomes (Rich et al., 2000).</p> <p>The concept of biographical disruption (Bury, 1982) has proven particularly influential in the application of a narrative approach to chronic illness. This posits that individuals with chronic illness undergo a process of narrative reconstruction in an attempt to reconcile their illness with the preconceived view of the self. However, this concept has emerged through the study of adult-onset illness where there is a shift from a 'normal' healthy state to one of illness. This neglects conditions that emerge in childhood, where the illness is perhaps part of the forming identity and where continuity is the guiding principle (S. Williams, 2000).</p> <p>One such condition is Cystic Fibrosis (CF) which is typically diagnosed within the first year of life and is therefore very much a part of the individual's developing sense of identity. CF becomes increasingly pronounced in adolescence resulting in frequent and lengthy hospitalisation which may impact on the individual's ability to establish supportive peer relationships. Given the importance of peer relationships in adolescence for the development of self identity (Erikson, 1968), this may have detrimental effects on long-term emotional adjustment and the development of a healthy self-concept.</p> <p>To date, there has been little research to explore the impact of CF in adolescence. That which has been done demonstrates that adolescents with CF struggle to form close peer relationships and that they try to appear 'normal' in an attempt to fit in with healthy peers (e.g. D'Auria et al., 2000). It is evident therefore that self-evaluative processes are at work as they compare themselves to their healthy peers. Nevertheless, it is unclear how adolescents with CF make sense of their experience of chronic illness within the context of trying to appear 'normal' and how this may influence the developing sense of self.</p> <p>In light of the foregoing, there is a need for research to explore the way adolescents with CF make sense of their illness, and the influence of their illness experiences on the developing self-identity. Thus, the major aim of this project is to explore the influence of CF on adolescents' developing self-identity, taking into consideration both the content and context of the story told. Accordingly, the following research questions will be considered:</p> <ul style="list-style-type: none"> (i) How do adolescents with CF make sense of their illness? (ii) What aspects of the self do they want others to see? (iii) What are the stories that are told when illness is a normal part of life?
<p>Q16</p>	<p>Brief description of methods and measurements:</p> <p>Design: A qualitative design will be employed for the purpose of this study, using a purposive sampling approach to recruitment. More specifically, a narrative approach will be employed to explore how young people with Cystic Fibrosis make sense of their illness through the stories they tell.</p>

	<p>Data Collection: data will be collected during single, lightly structured interviews which will begin with participants being asked to tell their story. According to Mishler (1986, 1995), within narrative research, the interview should be unstructured, to encourage participants to deliver sustained, detailed narratives of their experiences. However, young people may find the free recall associated with unstructured interviews frustrating and tiring, thus the use of prompts to aid the retrieval process is advocated (Steward & Steward, 1996). As such, both of the following approaches will be employed to structure the interview:</p> <p>Questions: questions may be used to open up topic areas that are identified from the literature to be important in the lives of adolescents with CF. Specifically, questions around relationships with peers and family, treatment regimes, perceptions of the future, body image, and the extent the illness impacts on day-to-day life.</p> <p>Photographs: Participants will be asked prior to the interview to take photographs to depict their lived experiences, which may then be used in the interview to facilitate the generation of narratives and to open up different topic areas. Research has shown that this approach may be effective in engaging young people in the interview process, and give them greater control over the content of discussions (Drew, Duncan, & Sawyer, 2010).</p>
<p>Q17</p>	<p>Participants: recruitment methods, study location, age, sex, exclusion/inclusion criteria:</p> <p>Participants: For the purpose of this study 6-12 participants will be recruited. This is to allow for two pilot interviews, with the actual number included in the final study being 6-10 participants.</p> <p>Inclusion criteria:</p> <ul style="list-style-type: none"> • Male/Female between the ages of 12-18years with a diagnosis of Cystic Fibrosis • Fluent English speaking <p>Exclusion Criteria:</p> <ul style="list-style-type: none"> • Males/Females with Cystic Fibrosis below the age of 12 years or over 18 years of age • Individuals with Cystic Fibrosis who cannot speak English fluently • Individuals with Cystic Fibrosis who have had a lung transplant or are on the waiting list for a lung transplant • Individuals between the ages of 12-18 years who do not have a diagnosis of Cystic Fibrosis <p>Recruitment Methods and Study Location: Participants will be recruited via specialist Cystic Fibrosis units within the NHS, and the Cystic Fibrosis Trust Facebook page. <u>NHS ethical approval will be obtained to cover the recruitment methods employed at the specialist Cystic Fibrosis Centres, therefore details relating to this are not provided here.</u></p> <p>Concerning recruitment of participants via the Cystic Fibrosis Facebook page, the researcher will place an advertisement on the page providing a brief summary of the research aims and procedure, asking those interested to contact them via a private message (see attached). Those who reply to this will then be asked for their email address and sent a copy of the information sheet along with specific instructions stating that if the participant is below 16 years of age, it will be necessary that their parents/guardians give consent for the young person to participate in the study, and requesting that they provide their parents/guardians with a copy of the information sheet.</p> <p>Potential participants will be given 10 days following receipt of the information sheet to state whether they wish to take part in the study. If the researcher does not hear anything in this</p>

time, they will send a brief reminder in case the young person has forgotten to respond. However, if the young person still does not respond, no further reminder will be given. Those who wish to participate will be asked to provide a contact telephone number and to agree a time when the researcher may contact them. It will be requested that if the young person is below the age of 16 years, a parent/guardian be present at this time so that verbal consent may be obtained from them. The phone call will be an opportunity to arrange a date, time, and location for the interview, as well as providing a forum for them to ask any questions they might have, though they will be advised that they may contact the researcher via email or private Facebook message with any questions. Concerning the location, participants will be offered the opportunity to conduct the interview in their own home, or at a convenient location where a private room can be arranged. Participants will be informed that we will ask to see them alone for the interview, but that they may have someone nearby if they would prefer. For those under the age of 16 years, it will be requested that their parents/guardians are present prior to the interview to provide written consent.

At this time, the process of obtaining photographs for the interview will be discussed with the participant and his/her parents if the person is under 16 years of age. An electronic copy detailing this information will also be emailed to participants to remind them of what was discussed (see attached). Participants will be invited to contact the researcher should they have any questions or concerns. Participants will be asked if they have their own digital camera/mobile phone that can be used to take photographs. Where participants do not have their own photography equipment, this may be borrowed from the University of Hertfordshire. The researcher will agree details of the loan with the participant at this time.

Participants will be asked to take 10-15 photographs that depict “what it is like to be you, as a young person with CF”. They will be asked to bring these along to the interview either as hard copies (i.e. printed out), or in digital format using a memory stick or CD-ROM disk. If they borrow a camera from the University of Hertfordshire, they will also be asked to return this at the interview. The participant will be informed that the researcher will bring a laptop computer to the interview to view digital versions of the photographs should they wish to bring digital copies.

Participants will be informed at this time that when they bring the photos to the interview the researcher will ask them if it is possible for them to retain a copy of the photos until the analysis is complete. It will be explained that this is because having the photograph present will ensure that the researcher may be able to more accurately recall what was discussed, which will assist with the analysis of the interview. However, they will be informed that it is up to them whether the researcher keeps a copy of the photos; they may choose for the researcher to have all of the photos, none of the photos, or a few of the photos. They will also be told that the photos will be returned to them once the analysis is complete, and will not appear in the write up of the study.

Following discussion of the procedure for the photographs, arrangements will be made for the interview, allowing approximately two weeks for participants to take the photographs that will be used to facilitate the interview. Any questions the participant may have about this will be answered by the researcher and participants will be able to contact the researcher via email prior to the interview should they have any further questions or concerns. For young people under the age of 16 years, the parent/guardian will be made aware that they may also contact the researcher with questions or concerns.

The interview will take place approximately two weeks after the initial telephone conversation. Approximately 2 days before the interview is scheduled to take place, the researcher will contact the participant to confirm the interview date, time, and location, and to ensure there have been no difficulties obtaining the photographs for the interview. Participants

will again be given the opportunity to ask questions, and will be asked if they are still happy to take part or would wish to withdraw.

The young person and researcher will meet alone for the main interview. In line with other research into personal experience of illness, it is considered important to meet with participants individually allowing each to express themselves as freely as possible. The need for individual interviews will be made clear in the information provided to potential participants and their parents before they consent to participation in the study, and again during the consent process. However, the presence of a parent/guardian in a nearby room is of course appropriate, given the age of some of the young people involved. Arrangements for refreshments/breaks will be made at the start of the session and reviewed carefully throughout the session to ensure the young person does not become fatigued/distressed.

The interview will employ a flexible, semi-structured interview design aimed at facilitating participants' expression of their lived experiences of CF. The participant will be invited to convey what s/he thinks it is most important for other people to know if they are to understand what it is like to be a young person living with CF. The interviewer will explain that she is interested in the individual perspectives of the young person and that there are therefore no right or wrong answers or things to say. As will have been discussed previously (prior to gaining consent) the interview will be audio recorded and later transcribed for review by the researcher.

The young person will be invited to bring between 10-15 photographs to the interview either printed or in digital format that depict their experiences of being a young person with CF. These will be used to facilitate a large part of the interview, encouraging the young person to present their views and experiences of living with CF. The researcher will also make use of a topic guide to ensure coverage of broad areas considered potentially important. This topic guide is influenced by previous research in similar fields of study (e.g. qualitative research conducted with young people with CF and other chronic conditions).

In this way, the interview structure will be flexible allowing the participant to direct the interview towards areas that are particularly important for him/her, and to control the depth of coverage of each of these areas. As such young people can be seen to have considerable influence on the research rather than being constrained by the preconceptions of adult researchers (as would be the case if the researcher, for example, employed a formal questionnaire). The flexible interview guide also allows the interviewer to adapt questions and prompts in response to the developmental level and personal style of each participant (e.g. simplifying language, providing more prompts). At the end of the interview participants will be asked whether they are happy for the researcher to retain a copy of the photos, on the understanding that they will be returned once the analysis is complete. They will be reminded that this is completely up to them, and that if they do not wish for the researcher to have a copy, that it will not affect their involvement in the study in anyway. They will then be offered the chance to reflect on the interview (debrief) and to ask any questions.

It is anticipated that the main interview will take approximately 60 minutes. However, this will be sensitive to the needs of the participants, particularly with respect to fatigue and physical discomfort. Participants will be reminded that they may take breaks when needed and continue at another time if preferred. The researcher will provide refreshments where interviews are carried out away from the participants' home.

At the end of the interview, participants will be debriefed and given the opportunity to ask any questions they may have. They will also be given advice concerning who they can talk to if they need further support or wish to make a complaint about the research (i.e. support groups, Research lead for the Department of Clinical Psychology) or if they have any further questions about the research (or wish to request a copy of the results – the researcher). They will be

	advised that should they have any concerns or experience any distress following the interview, they should contact the researcher immediately.
Q18	<p>Consent and participant information arrangements, debriefing:</p> <p>(see participant information sheet, consent forms, and debriefing forms attached)</p> <p>As noted above, participants will be given 10 days following receipt of the information sheet to provide verbal consent to taking part in the study. It will also be necessary to obtain verbal consent from the parents/guardians of potential participants below the age of 16 years at this point. Verbal consent will be obtained a second time, approximately two days before the interview is scheduled to take place.</p> <p>On the day of the interview, written consent will be obtained from all participants, along with written consent from the parents/guardians of those below 16 years of age. At regular intervals during the interview, participants will be asked if they are 'ok to continue' and will be reminded of their right to withdraw. Participants will be fully debriefed following the interview. Parents/guardians of those younger than 16 years of age will be offered the opportunity to take part in the debrief.</p>
Q19	<p>Any other relevant information:</p> <p>Participants will be reimbursed for any costs incurred through production of the photographs or travel to the interview (if they wish to meet at the University for example). Information relating to this will appear on the information sheets (see attached), though participants will be reminded of this at the outset of the meeting.</p>

SCHOOL OF PSYCHOLOGY ETHICS COMMITTEE APPROVAL

Student Investigator: Rebecca Adlington

Title of project: The Lived Experiences of Adolescents with Cystic Fibrosis (CF)

Supervisor: Wendy Solomons and Helen Davies

Registration Protocol Number: PSY/10/11/RA

The approval for the above research project was granted on 27 October 2011 by the Psychology Ethics Committee under delegated authority from the Ethics Committee of the University of Hertfordshire.

The end date of your study is 30 April 2012.

Signed:



Date: 27 October 2011

Professor Lia Kvavilashvili
Chair
Psychology Ethics Committee

STATEMENT OF THE SUPERVISOR:

From my discussions with the above student, as far as I can ascertain, s/he has followed the ethics protocol approved for this project.

Signed (supervisor):

Date:



Addenbrooke's Hospital
Respiratory Paediatrics
Hills Road
Cambridge
CB2 0QQ

01223 245 151

Date:

Study title: The lived experiences of adolescents with Cystic Fibrosis (CF)

Dear *(insert child's name/parent's names as appropriate)*

You/your child *(delete as appropriate)* is being/are *(delete as appropriate)* invited to take part in a research study to explore the experiences of young people with Cystic Fibrosis (CF). Please take time to read through the enclosed information sheet which contains details about why the research is being done and what it will involve. If you require any further information or wish to volunteer to take part in the study, please do not hesitate to contact me using the details below. Your/your child's *(delete as appropriate)* decision to participate/not participate in the study will not impact on the treatment you/your child *(delete as appropriate)* receive in any way.

Thank you for taking the time to read through this information.

If you/your child *(delete as appropriate)* are interested in taking part, or if you have any questions, please contact me:

Rebecca Adlington
Trainee Clinical Psychologist & Chief
Investigator
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

Or if you have any other questions, you
can contact:
Dr Richard Iles
Consultant Respiratory Paediatrician
Addenbrooke's Hospital
Hills Road
Cambridge
CB2 0QQ

by email: r.l.adlington@herts.ac.uk
or TEXT: 07793141547

APPENDIX E: YOUNG PERSON INFORMATION SHEET

I'm asking if you would like to talk to me, to help people understand what it's like for young people like you to live with Cystic Fibrosis (CF). Before deciding if you want to take part, it's important that you understand what this will involve. Please read this leaflet carefully, think about it, and talk to your family or friends about it if you want.

Why am I doing this research?

There has already been some research done with young people with CF which suggest that their experience of growing up with CF may influence their friendships and developing independence. But we don't know much about how they deal with these challenges or if they shape how they see themselves. Having a better understanding of these issues may help people provide better support for young people with CF in future.

Why have I been asked to take part?

Because you are aged 12-18 and have been diagnosed with CF - and your views are important. In total, I hope that about 12 young people like you will take part.

Do I have to take part?

No, it's up to you. Even if you decide to take part, you are free to stop at any time without giving a reason. Deciding to take part or not won't affect the care that you are receiving.

What will happen to me if I take part?

I will arrange to meet with you, at a time & place to suit you (e.g., your home your home, a private room in a local library, the hospital where you attend appointments). I will answer any questions you or your parents have. I will then ask you to sign a consent form, saying that you are happy to take part in the research. If you are under 16, your parent will also need to sign a form giving consent for you to take part (i.e., we need consent from both of you).

I will then arrange to meet with you around 2 weeks later to talk about your experiences of living with CF. In those two weeks, I will ask you to take photographs (about 10-15) which might help someone to understand what it is like to be you as a young person with CF. It is important that these show your own ideas. I will ask you to use your own digital camera or mobile phone to take the photos, though if this is not possible you may be able to borrow a digital camera.

You will be asked to bring the photos along to our meeting to help us to make sure that we talk about things that are important to you. You can say whatever you like - there are no right or wrong things to say! I am interested in what things are like from *your* point of view, we'll need to speak on our own, without family or friends in the room, though you may have someone nearby if you would prefer. The meeting will last about 1 hour, but we can stop/take breaks whenever you want.

At the end of the interview I will ask you if you would be happy for me to keep a copy of the

photographs, which will be returned to you once I have put together the findings of the study. It may be useful for me to have a copy of the photos to make sure that I remember them properly. However, it is OK for you to say if you do not wish for me to keep a copy of some or all of the photos. This will not affect your involvement in the study in any way. You may wish to discuss this decision with your family or friends before our meeting.

I will need to audiotape our conversations to make sure I remember them properly. Later I will write down what we have said, but I will remove any names and any information that might identify you or other people you speak about. Members of the research team at the University will check that everything has been written down and reported properly. At the end of the study, I will erase all tapes.

If you need to travel to our meetings or have to pay to produce the photos, keep your receipts, and I will refund this cost.

What are the risks of taking part?

There are no known risks. However, we will be talking about how CF has affected your life, and it may be that thinking about these things makes you feel upset. If this happens, you can talk to me, or if you want I can put you in touch with a psychologist or group for ongoing support. We have

had training to support people with upsetting feelings, and who live with illnesses like CF.

What if there is a problem?

If you would like advice or to make a complaint about anything to do with the research you can speak to me, your parents, or your health carer. Independent information & advice is available from PALS (Patient Advice and Liaison Service) on 01223 216756 or email: pals@addenbrookes.nhs.uk.

What are the benefits of taking part?

Taking part in this study will give you a chance to speak openly about your views and experiences, and you may find this a positive experience. Your contribution should help us gain a better understanding of what it is like for young people to live with CF. The aim is for this to lead to better treatment of young people with CF in the future.

Will anyone else know I'm doing this?

If you agree to take part, we will let your GP and doctor at the hospital know that you will be involved in a research project. However, we will not share anything that you tell us with them. We will keep your information in confidence, stored in a safe locked location. The only people who could see this would be members of the research team, and people who monitor research to check that it is being done properly. The results of the project will be written up in a report. This may include quotes from your interview, but all names and identifying details will be changed, so no-one will be able to tell who you are from it - what you say is confidential.

The ONLY time I would ever break this confidentiality is if I thought that you or someone else was at serious risk of harm, and I needed to speak to someone to make sure that you/they were safe.

Who is organizing & funding this research?

This research is being conducted as part of my Doctorate study, sponsored by the University of Hertfordshire. It is supported by Cambridge University Hospitals NHS Foundation Trust.

Who has reviewed the study?

Before any project like this goes ahead, it has to be checked by a Research Ethics Committee (REC). They make sure that the research is fair. This project has been checked by the Essex REC.

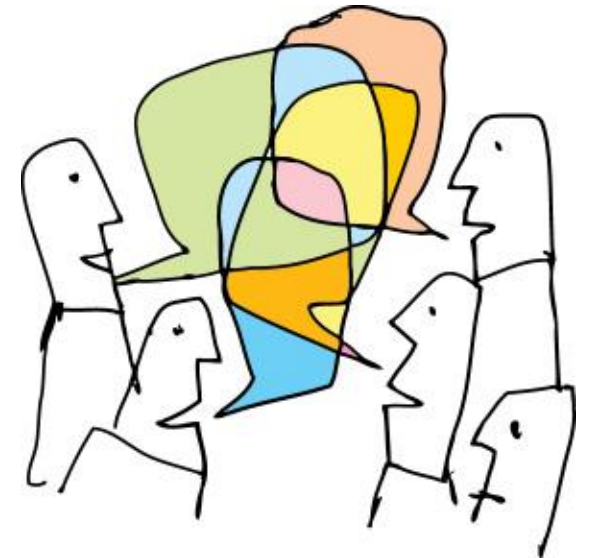
If you are interested in taking part, or if you have any questions, please contact me:

Rebecca Adlington
Trainee Clinical Psychologist
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

by email: r.l.adlington@herts.ac.uk
or TEXT: 07793141547

Or if you have any other questions, you can contact: Dr Richard Iles, Consultant Respiratory Paediatrician, Addenbrooke's Hospital, Hills Road, Cambridge, CB2 0QQ

The lived experiences of adolescents with Cystic Fibrosis (CF)



A research project that you might want to take part in

Addenbrooke's Hospital
Respiratory Paediatrics
Hills Road
Cambridge
CB2 0QQ

01223 245 151

Information Sheet for Parents

Study title: The lived experiences of adolescents with Cystic Fibrosis (CF)

Information about the research

Your child is being invited to take part in a research study. Before deciding whether to take part, it is important for you and your child to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your son or daughter and others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like your son or daughter to take part.

What is the purpose of the research?

There has already been some research done with adolescents with CF which highlights the challenges they may face in terms of forming close relationships with peers and developing a sense of independence. However, little is known about how young people make sense of these experiences or how they influence the developing sense of self. This research aims to increase our understanding of what it is like for young people to live with CF from their perspective. This may help people (e.g. health care providers, teachers, etc.) to provide better support for young people with CF in the future.

Why has my child been chosen?

Your child has been chosen to participate because s/he is aged 12-18 and has been diagnosed with CF. It is hoped that approximately 12 young people in Cambridgeshire will take part in this research.

Does my child have to take part?

No, it is up to you and your child to decide whether or not to take part. If your child does want to take part, AND you agree, you will both be asked to sign consent forms to show your agreement. (Children under 16 can only take part if *both child and parent* give consent.) However, your child is still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care they receive.

What will happen to my child if they take part? What will they have to do?

I will arrange to meet with you and your child at a time & place to suit them (e.g., your home, a private room in a local library, the hospital where your child attends appointments). At the start, I will answer any questions you or your child has, and then will ask you both to sign consent forms, saying that you are happy to take part in the research.

I will then arrange to meet with you again around two weeks later to talk to your child about their experiences of living with CF. In these two weeks, I will ask your child to take photographs (between 10 and 15 photographs) which might help someone to understand what it is like to be a young person with CF. I will ask that your child uses their own digital camera or mobile phone to do this, though where this is not possible, cameras can be provided. I will then ask your child to bring these with them when we meet so that we may talk about them. Although it may be useful for you to remind or encourage your child to take the photographs, it is important that they show your child's ideas and experiences.

I will then talk with your child about their experiences of living with CF. There are no right or wrong things to say - I am simply interested in what things are like from their point of view. For this reason, I will need to speak to your child alone, without any family or friends in the room – although it would of course be helpful if you are nearby, if your child would like this. The meeting will last about 1 hour, but we will stop or take breaks whenever your child wants. If we meet away from your home (e.g., at the University of Hertfordshire) I can provide refreshments for your child.

I will need to audiotape conversations with your child, to make sure I remember them accurately, but will erase the tapes at the end of the study. I will transcribe (write down in detail) everything that we have talked about, but when doing this I will remove names and any information that might identify your child or other people spoken about. Members of the research team at the University of Hertfordshire will check that everything has been transcribed and reported properly.

I will also ask your child if they are happy for me to retain a copy of the photographs during the period of analysis to make sure I remember them accurately. They will be told that this is completely up to them and it is ok for them to say no, or to withhold particular photographs. If they agree to give me copies of the photographs, these will be returned once the analysis is complete. The photographs will not be replicated or appear in the write up of the study. It may be helpful for you to discuss this with your child prior to the interview.

If you or your child incurs any expenses from participation in the study either through the production of photographs or travelling to our meetings, keep your receipts, and I will refund this cost.

What are the possible risks of taking part?

There are no known risks. However, we will be talking about how CF has affected your child's life, and it may be that thinking about these things could be distressing for them. If this happens, they can talk to me, or - if they want - I can put them in contact with a local clinical psychologist for ongoing support.

What are the benefits of taking part?

Taking part in this study will give your child a chance to speak openly about their views and experiences, and many young people find this a positive experience. Their contribution should help us gain a better understanding of what it is like for young people to live with CF. The aim is for this to lead to better treatment of young people with this condition in the future. Your child may also feel good to know that they are contributing in this way.

Will my child's part in this study be kept confidential?

All information which is collected will be kept strictly confidential. Any information about your child will be anonymised (i.e., have their name and other identifying details) removed so that they cannot be recognised from it. Information will be stored in a locked filing cabinet which may only be accessed by the researcher. Additionally, relevant sections of data collected during the study may be looked at by authorised individuals from Cambridge University Hospitals NHS Foundation Trust Research & Development team or regulatory authorities, who monitor the quality of all research to ensure that it is being conducted properly. The research team have a duty of confidentiality to your child as a research participant. The results of the research will be written up in a report, and this may contain quotes from the young people who have taken part – but all names and other identifying details will be removed, so they cannot be recognised from this.

Your child's paediatrician and GP will know that your child is taking part in the study. However, they will not know any details of what your child discusses in the interview. Disclosure of any personal information from the interview would only occur in exceptional circumstances, if your child revealed information that may indicate a risk to themselves or others.

If the researcher is worried about your child (for example, if they became very distressed when taking part in the interview), she will discuss it with them in the first instance. For some concerns (e.g., if she felt your child was very low or depressed), she would contact you to discuss this. In exceptional circumstances (e.g., if she is concerned that your child might harm themselves or other people, or is worried that someone else might be harming your child), she might have to talk to other professionals about these issues.

What will happen to the results of the research study?

The results of the research will be written up as part of my Doctorate in Clinical Psychology. All information will be carefully anonymised, so that none of the young people can be identified. A copy of the research will be kept in the University of Hertfordshire library. It is intended that the research will be submitted for publication in peer-reviewed journals and conferences, so that health professionals (and others involved in the care of young people with CF) can learn from this.

The written transcript of your child's anonymised interview will be kept in a secure location for five years, in line with University of Hertfordshire guidelines. After this time, it will be destroyed.

If you or your child would like a summary of the final results, please let me know.

What if there is a problem?

If you have any concerns or complaints about anything to do with the research, you or your child can speak to me, Rebecca Adlington, or your health carer. If you remain unhappy and wish to complain formally or seek independent advice please contact the Patient Advice and Liaison Service (PALS) on 01223 216756 or via email at pals@addenbrookes.nhs.uk.

Who is organizing & funding this research?

This research is being conducted as part of my Doctorate study, sponsored by the University of Hertfordshire. It is supported by Cambridge University Hospitals NHS Foundation Trust. The researcher has undergone all the usual checks (e.g., CRB) required by health professionals.

Who has reviewed the study?

Before any project like this goes ahead, it has to be checked by a Research Ethics Committee. They make sure that the research is fair and useful. This project has been checked by the Essex Research Ethics Committee.

If you and your child are interested in taking part, or if you have any questions, please contact me:

Rebecca Adlington
Trainee Clinical Psychologist & Chief Investigator
University of Hertfordshire
College Lane
Hatfield
AL10 9AB
by email: r.l.adlington@herts.ac.uk
or TEXT: 07793141547

Or if you have any other questions, you can contact:
Dr Richard Iles
Consultant Respiratory Paediatrician
Addenbrooke's Hospital
Hills Road
Cambridge
CB2 0QQ

This information sheet is for you to keep. A similar information sheet is provided for your child. If your child wishes to participate in the study, you will have a copy of the consent form to keep as well. Thank you for your time.

Addenbrooke's Hospital
Respiratory Paediatrics
Hills Road
Cambridge
CB2 0QQ

01223 245 151

Information Sheet for Parents

Study title: The lived experiences of adolescents with Cystic Fibrosis (CF)

Information about the research

Your child is being invited to take part in a research study. Before deciding whether to take part, it is important for your child to understand why the research is being done and what it will involve. As your child is 16-18 years of age, they will be able to give consent for themselves to take part. However, we hope that you may be able to support your son or daughter in making this decision, and would be happy to answer any questions you may have.

Please take time to read the following information carefully and discuss it with your son or daughter and others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the research?

There has already been some research done with adolescents with CF which highlights the challenges they may face in terms of forming close relationships with peers and developing a sense of independence. However, little is known about how young people make sense of these experiences or how they influence the developing sense of self. This research aims to increase our understanding of what it is like for young people to live with CF from their perspective. This may help people (e.g. health care providers, teachers, etc.) to provide better support for young people with CF in the future.

Why has my child been chosen?

Your child has been chosen to participate because s/he is aged 12-18 and has been diagnosed with CF. It is hoped that approximately 12 young people in Cambridgeshire will take part in this research.

Does my child have to take part?

No, it is up to your child to decide whether or not to take part. If your child does want to take part, he/she will be asked to sign a consent form to show his/her agreement. (Children under 16 can only take part if *both child and parent* give consent). However, your child is still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care they receive.

What will happen to my child if they take part? What will they have to do?

I will arrange to meet with your child at a time & place to suit them (e.g., your home, a private room in a local library, the hospital where your child attends appointments). At the start, I will answer any questions your child has, and then will ask him/her to sign a consent form, saying that s/he is happy to take part in the research.

I will then arrange to meet with your child again around two weeks later to talk to him/her about their experiences of living with CF. In these two weeks, I will ask your child to take photographs (between 10 and 15 photographs) which might help someone to understand what it is like to be a young person with CF. I will ask that your child uses their own digital camera or mobile phone to do this, though where this is not possible, cameras can be provided. I will then ask your child to bring these photos with them when we meet so that we may talk about them. Although it may be useful for you to remind or encourage your child to take the photographs, it is important that they show your child's ideas and experiences.

I will then talk with your child about their experiences of living with CF. There are no right or wrong things to say - I am simply interested in what things are like from their point of view. For this reason, I will need to speak to your child alone, without any family or friends in the room – although it would of course be helpful if you are nearby, if your child would like this. The meeting will last about 1 hour, but we will stop or take breaks whenever your child wants. If we meet away from your home (e.g., at the University of Hertfordshire) I can provide refreshments for your child.

I will need to audiotape conversations with your child, to make sure I remember them accurately, but will erase the tapes at the end of the study. I will transcribe (write down in detail) everything that we have talked about, but when doing this I will remove names and any information that might identify your child or other people spoken about. Members of the research team at the University of Hertfordshire will check that everything has been transcribed and reported properly.

I will also ask your child if they are happy for me to retain a copy of the photographs during the period of analysis to make sure I remember them accurately. They will be told that this is completely up to them and it is ok for them to say no, or to withhold particular photographs. If they agree to give me copies of the photographs, these will be returned once the analysis is complete. The photographs will not be replicated or appear in the write up of the study. It may be helpful for you to discuss this with your child prior to the interview.

If you or your child incurs any expenses from participation in the study either through the production of photographs or travelling to our meetings, keep your receipts, and I will refund this cost.

What are the possible risks of taking part?

There are no known risks. However, we will be talking about how CF has affected your child's life, and it may be that thinking about these things could be distressing for them. If this happens, they can talk to me, or - if they want - I can put them in contact with a local clinical psychologist for ongoing support.

What are the benefits of taking part?

Taking part in this study will give your child a chance to speak openly about their views and experiences, and many young people find this a positive experience. Their contribution should help us gain a better understanding of what it is like for young people to live with CF. The aim is for this to lead to better treatment of young people with this condition in the future. Your child may also feel good to know that they are contributing in this way.

Will my child's part in this study be kept confidential?

All information which is collected will be kept strictly confidential. Any information about your child will be anonymised (i.e., have their name and other identifying details) removed so that they cannot be recognised from it. Information will be stored in a locked filing cabinet which may only be accessed by the researcher. Additionally, relevant sections of data collected during the study may be looked at by authorised individuals from Cambridge University Hospitals NHS Foundation Trust Research & Development team or regulatory authorities, who monitor the quality of all research to ensure that it is being conducted properly. The research team has a duty of confidentiality to your child as a research participant. The results of the research will be written up in a report, and this may contain quotes from the young people who have taken part – but all names and other identifying details will be removed, so they cannot be recognised from this.

Your child's paediatrician and GP will know that your child is taking part in the study. However, they will not know any details of what your child discusses in the interview. Disclosure of any personal information from the interview would only occur in exceptional circumstances, if your child revealed information that may indicate a risk to themselves or others.

If the researcher is worried about your child (for example, if they became very distressed when taking part in the interview), she will discuss it with them in the first instance. For some concerns (e.g., if she felt your child was very low or depressed), she would contact you to discuss this. In exceptional circumstances (e.g., if she is concerned that your child might harm themselves or other people, or is worried that someone else might be harming your child), she might have to talk to other professionals about these issues.

What will happen to the results of the research study?

The results of the research will be written up as part of my Doctorate in Clinical Psychology. All information will be carefully anonymised, so that none of the young people can be identified. A copy of the research will be kept in the University of Hertfordshire library. It is intended that the research will be submitted for publication in peer-reviewed journals and conferences, so that health professionals (and others involved in the care of young people with CF) can learn from this.

The written transcript of your child's anonymised interview will be kept in a secure location for five years, in line with University of Hertfordshire guidelines. After this time, it will be destroyed.

If you or your child would like a summary of the final results, please let me know.

What if there is a problem?

If you have any concerns or complaints about anything to do with the research, you or your child can speak to me, Rebecca Adlington, or your health carer. If you remain unhappy and wish to complain formally or seek independent advice please contact the Patient Advice and Liaison Service (PALS) on 01223 216756 or via email at pals@addenbrookes.nhs.uk.

Who is organizing & funding this research?

This research is being conducted as part of my Doctorate study, sponsored by the University of Hertfordshire. It is supported by Cambridge University Hospitals NHS Foundation Trust. The researcher has undergone all the usual checks (e.g., CRB) required by health professionals.

Who has reviewed the study?

Before any project like this goes ahead, it has to be checked by a Research Ethics Committee. They make sure that the research is fair and useful. This project has been checked by the Essex Research Ethics Committee.

If your child is interested in taking part, or if you have any questions, please contact me:

**Rebecca Adlington
Trainee Clinical Psychologist & Chief Investigator
University of Hertfordshire
College Lane
Hatfield
AL10 9AB**

**by email: r.l.adlington@herts.ac.uk
or TEXT: 07793141547**

Or if you have any other questions, you can contact:
Dr Richard Iles
Consultant Respiratory Paediatrician
Addenbrooke's Hospital
Hills Road
Cambridge
CB2 0QQ

This information sheet is for you to keep. A similar information sheet is provided for your child. If your child wishes to participate in the study, s/he will have a copy of the consent form to keep as well.

Thank you for your time.

ASSENT FORM FOR YOUNG PEOPLE UNDER 16

Title of Project: The lived experiences of adolescents with Cystic Fibrosis (CF)

Name of Researcher: Rebecca Adlington (University of Hertfordshire)

Participant Identification Number: _____

If "Yes", put your initials in each box

Have you read (or had read to you) about this project?

Has somebody else explained this project to you?

Do you understand what this project is about?

Have you asked all the questions you want?

Have you had your questions answered in a way you understand?

Do you understand that if the researcher may have to share information given to him/her if s/he is worried that:

 Someone is at risk (e.g. of abuse, of self-injury etc.)?

 Someone is acting unprofessionally?

 Someone is involved in criminal activity?

Do you understand it's OK to stop taking part at any time?

Do you understand that you will be audio taped as part of the study?

Do you understand that we may use quotes of what you say in the final published write-up, & these will be anonymised (names will be removed)

Are you happy to take part?

If any answers are "no" or you don't want to take part, don't sign your name!

If all your answers are "yes" and you do want to take part, write your name

below:

Your name _____ Date _____

The researcher who explained this project to you needs to sign too:

Print Name _____

Sign _____ Date _____

CONSENT FORM FOR PARENT / LEGAL GUARDIAN

Title of Project: The lived experiences of adolescents with Cystic Fibrosis (CF)

Name of Researcher: Rebecca Adlington (University of Hertfordshire)

Participant Identification Number:

Please initial
boxes

1. I confirm that I have read and understand the information sheet dated September 2011 (Version 2) for the above study. I have had opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my child's participation is voluntary and that s/he is free to withdraw at any time without giving any reason, without medical care or legal rights being affected.
3. I understand that my child's interviews will be audio taped, and give permission for this.
4. I understand that when a report is written and published about the study, quotes from the interviews may be used, but all identifying information will be removed. I give my permission for publication of anonymised quotes.
5. I understand that relevant sections of data collected during the study may be looked at by authorised individuals from Cambridge University Hospitals NHS Trust or from regulatory authorities who check that research is being carried out correctly. I give permission for these individuals to have access to my child's records.
6. I understand that if the researcher is worried that someone (i.e. a child, participants, a member of the research team, or a member of the general public) may be at risk of harm (e.g. child abuse, self injury etc.), unprofessional practice (e.g. deviation from that which is acceptable), or criminal activity (e.g. NHS fraud) s/he will need to disclose this information to the relevant people or agencies (e.g. child protection agency, police etc.).
7. I give my agreement for my child to take part in the above study.

Name of Patient

Date

Signature

Name of Parent/Legal Guardian

Date

Signature

Researcher

Date

Signature

CONSENT FORM FOR YOUNG PERSON OVER 16

Title of Project: The lived experiences of adolescents with Cystic Fibrosis (CF)

Name of Researcher: Rebecca Adlington (University of Hertfordshire)

Participant Identification Number:

Please
initial boxes

8. I confirm that I have read and understand the information sheet dated September 2011 (Version 2) for the above study. I have had opportunity to consider the information, ask questions and have had these answered satisfactorily.
9. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my medical care or legal rights being affected.
10. I understand that my interview will be audio taped.
11. I understand that when a report is written and published about the study, quotes from my interview may be used, but all identifying information will be removed. I give permission for publication of these anonymised quotes.
12. I understand that relevant sections of data collected during the study may be looked at by authorised individuals from Cambridge University Hospitals NHS Trust or from regulatory authorities who check that research is being carried out correctly. I give permission for these individuals to have access to my records.
13. I understand that if the researcher is worried that someone (i.e. a child, participants, a member of the research team, or a member of the general public) may be at risk of harm (e.g. child abuse, self injury etc.), unprofessional practice (e.g. deviation from that which is acceptable), or criminal activity (e.g. NHS fraud) s/he will need to disclose this information to the relevant people or agencies (e.g. child protection agency, police etc.).
14. I give my agreement to take part in the above study.

Name of Patient

Date

Signature

Researcher

Date

Signature

TOPIC GUIDE FOR INTERVIEWS

Title: The lived experiences of adolescents with Cystic Fibrosis (CF)

At the start of the meetings, and prior to the main interviews, there will be:

- Introductions
- Opportunity for participants and parents to ask questions
- Reminders about recording, confidentiality, right to withdraw at any time etc
- Taking of signed consent forms (from participants; and from parents of those under 16)
- Noting of basic demographic information: age, checking contact details, health professional(s) ; ethnic / cultural background; school / education provider etc
- Discussion about and time to obtain photographs to facilitate the interview

The young person will then meet with the researcher alone for the main interview, which will be recorded.

The young person will first be reminded that:

- The research is focused on the young person's experience of living with CF, so - while the researcher will be asking questions & has some ideas about areas she's interested in, she is happy to be led by the young person and his or her ideas about what they feel it is important to focus on
- The young person does not need to answer any questions s/he does not wish to and should feel free to let the researcher know if there is anything s/he feels unhappy about at any time
- The young person should let the researcher know whenever s/he would like a break, or if s/he has had enough for that day; or no longer wants to continue
- There are no right or wrong answers

TOPIC GUIDE

NB – The first half of the interview will be concerned with the topics generated by the photographs. It is anticipated that some of the topics below may be covered in this. In light of this and to fit with each participant's narrative, the order of topics may be varied.

INTRODUCTION

Prior to the discussion of the photographs I will begin by obtaining relevant background information, by saying something along the lines of:

- "As I said before, I'm hoping to hear from you what life is like for you; but firstly, it would be good to hear a bit about you as a person, more generally... who you live with, what you like doing.... that sort of thing."

GENERAL BACKGROUND

Family	Who do you live with? Who else in your family are you close to/are important in your life?
Important others in your life	Adults (e.g. teachers, health care staff, family friends etc.) Friends Others (e.g. pets)
About you ...	How would you describe yourself? How would someone who knows you well (e.g. mum/dad/friend) describe you?
Interests	What sort of things do you enjoy (e.g. activities, music, TV etc.)? What do you enjoy doing now? Does having CF influence the kinds of things you enjoy doing? In what way? Is there anything that it motivates you to do that you wouldn't do otherwise?

INTRODUCTION TO THE PHOTOGRAPHS

A general preamble, something along the lines of "Can we go on to have a look at the photographs you have brought. What it would be useful to do is to think about each one individually, to consider what it shows and why or how that is important in your life. It may be that talking about one photograph leads us on to different topics or to a different photograph... that's ok, the important thing is that you feel you are getting the chance to tell me your story"

NB – Following the discussion of the photos we will go on to explore other relevant topic areas (identified below) that we may not have had the opportunity to cover.

LIFE WITH CF

- Can we talk now about CF and how it has affected you? *(Aim to elicit actual accounts of events, rather than just generalisations)*

EARLY CHILDHOOD

- "I'd like you to tell me a little bit about your early experiences of CF; what was it like for you as a young child?"

(Examples of possible prompts, if needed):

Physical symptoms	When did you first become aware that you had CF? What did you notice/Can you describe what happened? How did you understand/make sense of CF? Who helped you with this?
Healthcare & Medication	What was your experience of going to hospital appointments/treatments? Emotions/Physical sensations/Relationships with hospital staff/other patients
Social Interactions & School	How did others explain CF to you? Who helped you to learn about CF? Did you tell friends/teachers/others about CF? Did you tell different people different things? How did you explain it to them? What was their understanding? What did they notice? How did others seem to react (family/friends/teachers/others)? How did you feel about their reactions? Did it have any impact on your friendships? Did it have any impact on your progress at school? Did you know anyone else with CF/have support from groups, online organisations etc.
Activities	Did having CF influence the kinds of things you enjoyed doing in anyway? How did you feel about this?
Reflection (on all areas discussed)	How do feel about those experiences now?

HOW THINGS ARE NOW

- “I’d like us to think about your life now, what it is like for you to be an adolescent. Tell me a bit about your life now”

(Examples of possible prompts, if needed):

Physical symptoms	Have you noticed any changes in your physical symptoms? What have you found helpful in managing your symptoms?
Healthcare &	What are your experiences of your day-to-day treatment routines?

Medication How do you feel about them?
How easy are they to stick to? Does anything make it difficult to stick to treatments? (i.e. because it stops you from going out/doing things you want to do/you forget etc.)
Who is responsible for your treatment? Has this changed as you have got older? How was this decided?
What are your experiences of going into hospital (increased visits/length of stay/staff support/peer support)

Social Interactions & School Who worries about you most? What is this like for you?
Who is the biggest source of support for you?
How do others (peers/teachers/society) understand CF?
Do you tell others about CF?
What do others (peers/teachers/society) notice?
How do you think others (peers/family/teachers/society etc.) see you?
How would you like to be seen by others?
How do you find school work?
How do you keep in touch with friends? What kinds of things do you do socially?
Are there times when you have to miss periods of school? How do you keep in touch with friends?
Do you know anyone else with CF/have support from groups, online organisations etc.

Activities Does having CF influence the things you enjoy doing in anyway? In what way?
How do you feel about this?

Reflection (on all areas discussed) Do you think this will change in the next 5 years/next 10 years?

PUTTING YOUR CURRENT EXPERIENCES INTO CONTEXT

- “Do you think your life with CF differs from the lives of other teenagers who don’t have this condition?”

(Examples of possible prompts, if needed):

Autonomy What does independence mean to you?
In what ways are you independent?
Are there ways in which you would like to be more independent? How independent do you think others your age are?

Activities/Social How do you view your social life?
Does having CF influence your social life in any way? If yes, in what way?

Do you think things are different for your friends who do not have CF? If yes, in what way?

- “How do you think your life might be different when compared to:
 - Young children with CF/your early experiences of CF?
 - Adults with CF?
 - People of the opposite gender with CF?
 - People with CF from different cultural backgrounds?
 - Teenagers with CF 10 years ago?
 - Teenagers with CF 10 years from now?

(Examples of possible prompts, if needed):

Differences	How might things be different? What mightexperience?
Role of treatment and technology	Advances in treatment Role of technology (i.e. social networking sites, mobile phones, email and messenger etc.)

THINKING ABOUT THE FUTURE

- “What do you think your life will look like 1 year from now/5 years from now/ 10 years from now?”
- “What are your hopes for the future?” (*Prompts: social/academic/career/health/marriage/ children etc.*)
- “Have you thought about how CF might influence your life in the future?” (*Prompts: as above/possible treatments- lung transplant etc.*)
- “What do others (parents/siblings/friends/teachers) think about your thoughts on the future?”
- “Do your beliefs about the future influence how you live your life now?” (i.e. emphasis placed on school and relationship etc.)

REFLECTIONS & IDENTITY

- “Overall, would you say you differ as a person from those around you, as a result of your experiences of living with CF?” “If yes, in what way?”
- “How do you think you/your life would be different if you did not have CF?”
- “What are the positives/things you have learned as a result of your experiences with CF?”
- “If you could give a message to the world, what would you tell them about CF?”

TO END

- How has this been, talking to me today?
- Are there any other things that you think it is important for me – or other people – to understand about you, and your experiences with CF?
- Are there any things that you want to say more about?
- Any things that you're feeling uncomfortable about having said? (Any things that you don't want to be included in your account?)

Closing up... RA contact details in case participant needs to get in touch etc, how the information will be used etc.

Obtaining Photographs for the interview

Study title: The lived experiences of adolescents with Cystic Fibrosis (CF)

What you will need to do

The aim of this study is to get a better understanding of what it is like to be a young person with CF. As such, it is important that the interview deals with the things that are important to you.

To help us to do this I would like you to bring along to the interview 10-15 photographs which you believe show what it is like to be you, as a young person with CF.

The photographs can be of places or objects (not people) - anything that you feel would help someone else to understand your life, though it would be helpful to include ideas from different areas of your life (e.g. school, home, treatment, etc.). It is important that you decide what to include.

As we have agreed, you will have two weeks to take your photographs before we meet for the interview.

Bringing the photographs to the interview

To make sure we can look at the photographs, you may print them out or put them onto a CD-ROM disk or memory stick. I will bring along a laptop computer so that we may look at the photos during the interview.

If it costs you anything to print the photos or put them on a disk, please keep receipts and I will refund you (you may ask your parents to do this if you are not sure what to do).

After the interview

Once we have finished the interview, I will ask you if it would be ok for me to keep a copy of the photos to help me to remember what they show when I listen back to the interview. If you are happy for me to keep a copy, these will be returned to you once I have put together the findings of the study. If you do not wish for me to keep a copy of the photos, or would prefer me to have copies of only certain photos, this is ok, and will not affect your involvement in the study in any way. You may wish to discuss this with your family or friends before we meet for the interview.

Any Questions?

If you have any questions about any of this, please feel free to email me at r.l.adlington@herts.ac.uk and I will be happy to help you.

I look forward to seeing you and your photographs at our next meeting

Thank you for taking the time to do this

What happens next ...

Study title: The lived experiences of adolescents with Cystic Fibrosis (CF)

THANK YOU for taking part in the study. I hope you found this a useful and enjoyable experience. What you have told me about your experiences of living with CF will be used to help us to get a better understanding of what it is like to be a young person with CF. It is hoped that this will lead to better treatment and support for young people with CF in the future.

As discussed, if you are happy to continue your involvement in the study, I will contact you again in 6-8months to share with you the findings of the study which will be based on the ideas of everyone who took part in the study. You will have the opportunity to discuss the findings with me; to say whether they accurately reflect what it is like to be a young person with CF, and whether you think anything else should be included.

If in the meantime, you have any questions or concerns about any part of the study, please feel free to contact me and I will be happy to discuss these with you. If you wish to withdraw from the study, you may do so without giving a reason. This will not affect the care you receive in any way.

If you have any questions, please contact me:

Rebecca Adlington
Trainee Clinical Psychologist & Chief Investigator
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

By email: r.l.adlington@herts.ac.uk

or TEXT: 07793141547



Doctorate in Clinical Psychology
University of Hertfordshire

Transcription confidentiality/ non-disclosure agreement

This non-disclosure agreement is in reference to the following parties:

Rebecca Adlington

And

Transcription service: HW Secretanal Services

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.

Signed: H Williams
Name: H. WILLIAMS
Date: 24/2/12



Major Research Proposal

Student No:
1.

APPENDIX O: VERBAL SUMMARY OF THE INFORMATION CONTAINED IN THE PHOTOS

AMY
<ol style="list-style-type: none"> 1. A Labradoodle puppy sat on what appears to be the kitchen floor. Photo slightly blurred as if the dog had moved. 2. Amy stood in-between two girls all smiling for the camera. All are wearing make-up and dressed as if going out. Amy looks significantly older in the photo than she appeared during the interview. 3. Approximately 14 girls and one boy (all appear a similar age) sat on an L-shaped couch, all dressed up as if about to go out. Amy is in the middle with her arm around one of her friends. Some of the people in the photo, including Amy are smiling for the camera, others are talking as if they may not have realised the photo was being taken. 4. A man in his late forties- early fifties (identified as her dad) sat on the floor in front of a couch with a brown labradoodle sprawled out at the side of him. His attention is on the dog rather than posing for the camera. 5. A younger girl (identified as her sister) who looks similar to Amy, pulling a funny face as she takes a photo of herself. Her arm can be seen in the shot as she is holding the camera and part of her head is out of the frame. 6. Picture of the same girl as before walking a large labradoodle. Dressed for winter weather in wellington boots a large coat, hat, and gloves. 7. Amy alone, posing for the camera. Taken on the same night as the earlier pictures of her according to what she is wearing etc. She is not smiling but striking a 'model' pose. 8. A girl in her early twenties (identified as Amy's half sister), sat on a couch watching a man of approximately the same age (identified as the girl's boyfriend) open a Christmas present. Both are smiling but appear unaware of the camera.
MIRANDA
<ol style="list-style-type: none"> 1. A copy of her school planner, lying on a table. On the front of the planner are four pictures of areas in her school. 2. Her running kit, which consisted of silver trainers and two high visibility vests, laid out on the floor. In the middle of them all is a trophy. 3. A picture of five stuffed toys sat in a row on her bed. From left to right these include a brown bear wearing a cream infant's dress, a tiger wearing a pale pink infant's dress, a Dalmatian dog, a sandy coloured dog with a darker brown patch around one eye and brown ears, and a pink teddy bear. 4. A pencil and crayon drawing of a dark and light blue dress – the colours alternating along in a series of layers on the skirt of the dress. 5. A purple One Direction hooded top laid out on the floor. The left sleeve is positioned as if bent at the elbow and tucked into the bend is a One Direction CD sleeve. 6. Miranda with her arms crossed across her chest, her new puppy cradled in her arms. Both are looking directly at the camera and Miranda has a slight smile on her face. 7. Reward chart: a cupboard door upon which is the initials of Miranda and her two siblings. Stuck below each initial are numerous laminated faces of celebrities that appear to have been taken from magazines.
CLAUDIA

1. A teddy bear sat with a red bandana across on its head, sat centre frame on a white quilt.
2. A tall hot chocolate in a glass with a love heart pattern in chocolate powder on the top.
3. Claudia alone, with pensive facial expression. She is wearing a blue hospital gown and her flowery boots. She has a cannula in her hand. She is sat on a chair outside a door clearly marked radioactive.
4. Claudia's hand resting on her knee, with a cannula in the back of her hand held in place by a bandage (not discussed as she said it related to previous photo).
5. Claudia and her friend, both facing the camera and smiling with heads tilted together.
6. Claudia's floral doc martin boots. Photo is taken while she is wearing them, but angle would suggest they were taken by someone stood in front of her.
7. Claudia with another friend both dressed smartly and stood together posing for the photo in what looks like a church.
8. Picture of a photo of One Direction, which appears to be at the bottom of a magazine article.
9. A group of 9 girls taken at a bowling alley, with the lane behind them. Claudia is stood second from the end with another girl and both appear to be bending their knees.
10. Claudia and a friend wearing face packs, posing against a white painted wall, heads close together, laughing. Claudia's hair is tied back and piled high on her head.
11. The cover of a program for Grease the Musical, signed by members of the cast. Presented against a plain background.
12. A Ticket for a Diversity concert. Photo taken so ticket takes up the whole frame.
13. Claudia's nebulizer with vial of medication for use with it. Nebulizer placed on a white desk and in the corner of the frame is a copy of 'Now' magazine.
14. A pink and white striped towel with 8 swimming badges neatly sewn in a line along the bottom. Picture taken so towel takes up the entire frame and badges are clearly visible, making it possible to read what each of them were for.
15. Three large Galaxy chocolate bars, a Malteser bunny, a Cadbury's flake, a box of Maltesers and a box of Ferrero Rocher placed together on a bedside table.
16. Claudia with a 2/3yr old boy who she named as her cousin. Both are wearing paper Christmas hats and are sat at a dinner table with what looks to be the remains of Christmas dinner in front of them. Claudia is looking at the camera and smiling while the boy is looking at her.
17. Girls Aloud concert ticket. Photo taken so ticket takes up the whole frame.

ROB

1. A black PlayStation console positioned on the corner of a desk, with the corner of a flat screen TV clearly visible next to it.
2. White sign with the word 'danger' in a red circle surrounded by a black rectangle, below which it says 'Rob's room' in black lettering. All the writing is in capital letters.
3. An un-made bed, with blue and white sheets. The duvet is crumpled up in the centre of the bed and pillow is positioned at an angle at the top of the bed with what appears to be a mobile phone sticking out from underneath it. White walls, a brown carpet, and a green radiator are also visible.
4. Part of a French stick and two unopened packets of Walkers slat and vinegar crisps are

positioned on a chopping board along with a bread knife, on a marbled kitchen work surface.

5. A large flat screen TV stood on a dark wood unit with a white wall behind. On the TV is an image of Simon Pegg buying groceries in an American convenience store, taken from the movie 'Paul'.
6. A close up of the corner of a computer screen with the cursor positioned next to the word 'Facebook'. Behind the computer, the fire place of the living room is clearly visible.
7. Close up of a TV screen showing a football commentator against a green background, with football match results scrolling along the bottom of the screen.
8. A wider shot than above of the same programme at a different point. In this instance two men are present on screen.

DANIEL

1. A blue nebuliser sat on a kitchen work surface
2. A blue nebuliser with a second attachment, again sat on the work surface
3. Another photo of the nebuliser, with a square blue electronic device sat next to it which he identifies as "the active bit"
4. A transparent plastic green-blue device sat on the kitchen work surface which he identifies as his Acapella
5. A transparent plastic device comprised of two cylinders and a blue tube coming away from it and disappearing out of shot. In the smaller cylinder is a little yellow ball, and faces are marked on the outside. It is not possible to see the expression on the bottom one but the top face is sad and the middle is happy.
6. The Acapella taken apart and lying on a green towel on the kitchen work surface as if laid out to dry.
7. A Nike basketball positioned centre frame on a wood panelled floor
8. A muddy football boot positioned centre frame, on a grey slate floor against the bottom of a wooden cupboard.
9. A kitchen cupboard (identified as the medicine cabinet) with four shelves. Daniel identifies the shelf second from bottom to be the one containing his medication. Compared to the other shelves, this is very full, with boxes stacked on top of one another
10. A silver plastic basket containing tablet boxes, a purple inhaler, and a medicine bottle. Identified as more of Daniel's medication
11. A close up shot of Daniel's shelf in the medicine cabinet, focused in on the word 'Creon' on one of the boxes

SARA

1. Two cats, one ginger, and one black and white sat on a green plastic garden chair which is positioned next to a high wooden fence. Both are looking at the camera. Shadows of nearby shrubbery suggest it was taken on a sunny day.
2. Picture of a woman with dark hair, glasses, and a green top, smiling at the camera. The angle of the photo would suggest that she is holding the camera in both hands. Kitchen cupboards can be seen in the background.

3. A young girl of approximately 3 years of age with blonde hair, wearing a blue and white dress. She is sat in front of a computer keyboard with her hands hanging in the air as if she is about to type. She is smiling at the camera.
4. A woman with dyed red hair and brown top, stood behind a young girl of approximately 4 years of age, with blonde hair and a pink and blue dress. Both are looking directly at the camera. The woman is smiling; the young girl appears interested in the camera.

CONSENT FORM FOR INCLUSION OF TRANSCRIPT IN APPENDICES YOUNG PERSON OVER 16

Title of Project: The lived experiences of adolescents with Cystic Fibrosis (CF)

Name of Researcher: Rebecca Adlington (University of Hertfordshire)

Participant Identification Number:

Information

Within interview research it is necessary to be clear about how the researcher reached their conclusions about the main findings of the study. For this reason, we would like to include a transcript of your interview in full, in the appendix section of this study.

If you agree:

- This would be available in the copies for examination only (i.e. it would only be read by the two examiners)
- This would be fully anonymised with any names/identifying information (e.g. names of others, places etc.) removed/changed.

You do not have to say yes, this is completely up to you. You may find it helpful to discuss this with others before making your decision. Alternatively, if you have any questions for the researcher, please contact her using the details below.

Rebecca Adlington
Trainee Clinical Psychologist & Chief Investigator
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

by email: r.l.adlington@herts.ac.uk
or TEXT: 07793141547

Agreement

If you are happy to give your consent for your transcript to be used as set out above, please sign below.

Name of Patient

Date

Signature

Researcher

Date

Signature

When completed: 1 copy for participant; 1 copy for researcher

APPENDIX Q: AMY'S TRANSCRIPT AND ANALYSIS

Included only in the examiner's copies