LIVING AT THE EDGE: NARRATIVES OF YOUNG PEOPLE SURVIVING CYSTIC FIBROSIS

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Statement of Authentication

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

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ABSTRACT

This study discusses the narratives of twenty-one young people living with a genetic disease called Cystic fibrosis (CF). It explores how these young people take up subject positions and subjectivities in managing their condition within the medical discourse of CF. The narrative data was analysed using a poststructuralist framework in order to understand young people’s subjectivity.

This thesis attempts to challenge the positivist view that uses objective measures to assess young people’s attitude towards their use of medication to stay alive. It disputes a moralizing stance towards non-compliance / non-adherence and opens up a space to consider young people’s attitudes in a different light.

The analysis focuses on three main themes in the young people’s relationship with the discourse of CF: ‘normalization’, ‘resistance’ and ‘performativity’. The theme of normalization is taken to mean the ways these young people position themselves to ‘pass-as-normal’, in their attempts not to be totally colonized by CF. Resistance is taken to mean how these young people subvert the medicalised discourse of CF and use intelligent compliance in their relationship with their medications. The last analysis uses the concept of performativity to understand how young people take up their agency to carve out a livable existence within the discourse of CF. In their acts of agency, these young people did not subvert the medical discourse completely but used it intelligently to constitute themselves.

This thesis concludes with the view that, while the medical discourse of CF is necessary and vital to the survival of these young people, this discourse need not dominate them. The study opens up alternative possibilities for engaging with these young people in ways that are not reducible to the powers of surveillance.
Prologue

Heredity

Inescapably, this is me --- the diagnosis
Is cause for anger at those
Who brightly say we chose our destinies.

There is no store
Of courage, wit or will
Can save me from myself and I must face
My children, feeling like
That wicked fairy, uninvited
At the christening, bestowing on my own,
Amidst murmurs of apprehension, a most
Unwanted gift -- that
Of a blighted gene. No one
Could tell me of this curse when I
Was young and dreamt of children
And the graces they would bear. Later
It seemed that a chill morning
revealed deeper layers
of truth. For my romancing
There is a price to pay---
Perhaps my children’s children
Will pass this tollgate after me.
My grandmothers gaze down from their frames
On my wall, sadly wondering.

Meg Campbell.
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CHAPTER 1
INTRODUCTION AND OVERVIEW OF THE STUDY

1.1 Introduction and background

It is an interesting conundrum that this study is made possible and relevant by the very discourse that it also brings into partial dispute: the medical discourse surrounding young people with a diagnosis of Cystic Fibrosis (CF). If it were not for relatively recent, life-extending advances in medical technology, the young people whose stories are narrated and analyzed in this thesis would not necessarily have lived to ‘tell the tale’ of living with CF.

Since the Second World War, advances in medical technology have changed the management of chronic diseases including CF. The changes involve technologies for early diagnosis, as well as cutting edge intervention with newer and more effective drugs. Advances in cytogenetic and molecular genetic research have extended the lives of those living with CF.

Thus my research participants (whom I interviewed between 2002 and 2006) are from one of the first large generations of young people living with CF who may reach adulthood (Australian CF foundation data 1998). Because of medical advances, more people diagnosed with CF may now expect to reach middle age. Population and survival studies of CF, by Fitzsimmons and by Dodge et al, in the UK found that for every decade the life expectancy is increased by another ten years because of medical advances (Dodge et al., 1997; Fitzsimmons, 1993). In addition, in 2004, the American CF Foundation estimated that in their CF population group, one third of their CF patients were over the age of eighteen (CF Foundation data, http://www.ccf.org). What was initially a paediatric disease (Patton, Ventura, & Seavedra, 1986) has now also become an adult disease.
It seems that CF has now ‘grown up’. Significantly, the first book ever to be written solely on adult CF disease was published at the turn of this century by two CF specialists (Yankaskas & Knowles, 1999). This marks a milestone in CF management of adults and marks the fact that CF is no longer just a childhood disease.

As the life expectancy of CF sufferers increases, so does the imperative to manage complications through timely treatment. Lung infection is the greatest single complication facing people living with CF, because lung complication means a less than effective way of delivering oxygen to the system, and without oxygen, death is the only outcome. The current increasing survival rates can be attributed to a clearer understanding of the lung pathogenesis leading to a more accurate means of diagnosis. Additionally, the sixties hailed the availability of drug therapy, such as antibiotics, that has allowed for greater efficacy of treatment of lung infections and has slowed the progression of pulmonary complications and scarring of the lungs due to repeated infections (Doershuk, Matthews, Tucker, & Spector, 1965; Garred et al., 1999). This has enabled young people living with CF to benefit from this treatment by decreasing their hospital admissions.

Malnutrition is another complication besetting young people living with CF at all the stages of their life. The unravelling of the CF gene in the late eighties (Tsui et al., 1985) led to the discovery of recent new genetic screening technologies for CF (Boyne, Evans, Pollitt, Taylor, & Dalton, 2000). This enabled earlier detection and more accurate diagnosis (Farrell et al., 2001), which in turn allowed for speedier intervention and treatment. The timely treatment with the enzyme pancreas has helped in preventing malnutrition because one of the earliest issues of the CF disease is the inability to synthesise fatty acids. Those born in the nineties with CF are predicted to live to an average age of forty years or more (Elborn, Shale, & Britton, 2000).
The longevity of young people living with CF has meant the focus of care is no longer being limited to keeping the patients alive, but has been extended to that of attempting to medically enhance the quality of life. This imperative, to not only prolong life but to maximise its quality, is interwoven with the discourse of compliance. For instance, treatment of lung infections can lead to the preservation of lung tissues and assist in the ability to synthesise oxygen, but to be effective, the treatment must be timely. This in turn increases the focus on ‘patient compliance’.

1.2 Purpose and scope of study

The possibility of early death through complications is always a reality for young persons living with CF. My research seeks to understand how these young people living with CF deal with growing up with CF and living beyond their expected lifespan. The aim of this qualitative study is to gain an understanding of the lived experience of young people who have survived a potentially fatal complex genetic disease. Their life is a constant dilemma because there is no cure; hence, medical treatment is at best prophylactic, limited merely to managing symptoms of the disease.

This research focuses on young men and women between the ages of 13 and 18 in order to enable me to understand how they deal with transition into adulthood, as well as the personal, social and psychological impact of having a terminal genetic condition. I am particularly interested in the relational strategies these young people adopt and their ways of making sense of their life within the context of their disease conditions. The majority of my participants involved in this study were born in the late eighties. These were the participants whose parents were told that their child may not survive past school age, yet have beaten the odds and are living into early adulthood.

Currently there are around 500 young people under the age of 18 in New South Wales, Australia, living with CF. Each year around 20 new cases are
expected to be diagnosed. It has been predicted that the number of new cases of CF may not diminish, due to the unavailability of population screening for carriers of the CF gene; this is still true now because general population screening for CF is not realistic since there are over 800 mutations within the CF gene (Simpson et al., 2005; Watson et al., 2004).

1.3 The research problem and research question

The idea for this thesis began whilst I was working as a team member in the CF clinic of a large public hospital. I observed that psychosocial care appeared to be of low priority in the treatment of people living with CF (Blair, Cull, & Freeman, 1994). The medical guardian of this disease, it seemed, did not consider its genetic, psychological and social implications to be of interest. The CF book by Yankaskas and Knowles was 485 pages long and devoted only 10 pages to the social issues of adults (Yankaskas & Knowles, 1999). This observation was also voiced by Harper, a geneticist and physician (Harper, 1994) who was critical of a predominantly medical focus in the care of patients with a genetic condition, thus ignoring the genetic, the psychological and the social implications.

Apart from my role as CF co-ordinator, I was also involved in the children’s emergency department as a registered nurse. I found that the medical model of care was central to the practices in the emergency department. The medical model of care is thought to be the most efficient life saving route for acute medical emergencies. It was within the walls of this department that I experienced young people surviving CF being admitted with self-harm, as well as exacerbation of their disease through infections. Whether these problems arose through neglect or non-compliance is largely unknown. What is known is that non-compliance or non-adherence to the medical regime leads to a deterioration of the health status of young people living with CF, particularly an increased rate of pulmonary infections (Fitzgerald, 2001).
Whether this increase in pulmonary infection was due to neglect in lung physiotherapy or to not adhering to the use of nebulised tobramycin is unclear. It can also be very difficult to distinguish whether infections are a result of non-compliance or just ‘bad luck’.

It is within a paradigm of ‘caring’ [where Kattow (2001) distinguished between doctors as curers and nurses as carers] that I wanted to understand the young people whom I met in the daily course of my working life. In my professional capacity as a genetic counsellor, the avenue open to me to achieve my goal would be to find an alternative way to care for these young people. As someone working with these young people, I am interested in the possibilities of providing holistic care that is in tune with their needs. There is some tension in my positioning in that I wish to support young people living with CF both to live as ‘normally’ as possible and to comply with life-supporting medical regimes.

A great deal of CF care is informed by the medical model, and I do not dispute its centrality to the survival of these young people. However, I do question medical discourse in terms of its production of resistance in the form of non-compliance. I am interested in the phenomenon of non-compliance, because the published studies do seem to indicate that non-compliance with medical advice is a serious issue (Abbott, Dodd, Gee, & Webb, 2001; Llorente, Gracia, & Martin, 2008; Zindani, Streetman, Pharm, Streetman, & Nasr, 2006). The kinds of studies done to date do not shed any light on young people’s thinking about compliance (Sameroff, Lewis, & Miller, 2000; Shaw, 2001). In my study, I interviewed young people in my care, in order to gain some insight into the issue of non-compliance. It is hard to understand why young people might not comply, given the dire effects of non-compliance. However I am not so much interested in whether they comply or not - what I am interested in is how they think about compliance, and how they think about CF.
The traditional practice within medicine highlights studies of the so-called 'normal' in order to distinguish its binary the 'abnormal'. Within this model of care, health professionals use normal values of vital signs and electrolyte levels to access any variations from the 'norm', (Browne, Choong, Gaudry, & Wilkins, 1997, p. 418). Rather than measuring young people according to norms, my data analysis looks at what they say; mapping how compliance with or resistance to medical regulation are constructed in relation to how young people think about themselves and their peer relationships. This may help me understand how these research participants construct compliance to the medical regime as intrinsic or intrusive to their lives and relationships as young people. In order to analyse what they say, I look at their narratives and the relational strategies they talk about. In addition I include an analysis of how they position themselves (Davies & Harre, 1990) in relation to their peers, how they 'pass' as 'normal', what strategic resistance they use and what 'performative masquerade' (Riviere, 1986), they take on to live a viable life as a CF young person. The young people I interviewed were considered by the CF team to be among the healthiest, so my sample reflects more 'positive' attitudes than if I had interviewed young people in very poor states of health. Nevertheless, I was surprised by the degree to which the young people in my study were able to pass as normal, resist pathologising subject positions, and perform beyond the predictions of medical discourse.

1.4 Contextualising the study

The increasing survival of young people living with CF can culminate in complex outcomes involving their health. Chronic and aging conditions

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1 Health care professionals carry with them a pocket edition of normal vital signs, electrolytes levels and haematology levels. These data are used as a yardstick to measure deviant results.

2 As I was a member of the CF team at the time when I commenced this research, I had to obtain consent from the CF team to recruit the young people in our care. The conditions of the recruitment were that I was only allowed to recruit the young people NOT under the care of the mental health team because the team felt that I might compromise the care provided by the mental health team.
occur more prematurely than in the general population (Yankaskas, Egan, & Mauro, 1999). In the general population, age-related chronic conditions usually set in during the sixth to seventh decade, but in the CF population destruction of their lungs and livers, and Type II diabetes, can set in as young as in their teens and twenties (Cowen et al., 1984). These critical problems need to be addressed in a timely fashion to allow for good chances of survival and acceptable quality of life.

In addition, all these young people carry one copy of the genetic material, which can be passed on to their children. Since CF is a recessive genetic condition, both partners will have to be carriers of the genetic material for them to have a one to four chance of conceiving a child with CF. As mentioned earlier, without population screening for carriers of the CF gene, it is difficult to ascertain the carriers of the CF gene. This is a concern because of the high carrier status of CF, with a frequency of twenty-five per hundred carriers in a Caucasian population. This high frequency means that the chance of two carriers meeting and having children is high.

1.41 The global context of Cystic fibrosis

In the USA, Hilman and Aitken raised the complex question of the increasing life span of women living with CF, and subsequent reproductive issues (Hilman & Aitken, 1996). Similarly, concerns were also aired in Britain (Hamlett, Murphy, Hayes, & Doershuk, 1996), with regard to women living with CF surviving into reproductive age and embracing motherhood. One concern raised regarding motherhood was whether pregnancy may complicate the disease situation, placing more stress on an already stressed liver (Lyons et al., 2006). Another concern was the possibility of the child being orphaned if the mother’s survival may be threatened prematurely (Johannesson, 2002; Simcox, Duff, Hewison, Morton, & Conway, 2006).
Fatherhood has been regarded as a problem too, although most males living with CF are known to be sterile due to an anomaly called congenital bilateral absence of the vas deferens (CBAVD) (Hodson & Geddes, 2000). Recently two articles discussed the possibility of men living with CF having children. Both men fulfilled the United States CF Foundation diagnostic criteria, yet had viable sperm (Barreto, Pinto, Duarte, Lavinha, & Ramsey, 1991; Crowley & Bush, 2002). These two articles highlight the possibility of men being fertile and the problems of unintended transmitting of the CF genes to the next generation by men.

1.42 The Australian context of Cystic fibrosis

Since Australia is a relatively young country in the history of Caucasian settlement, the population demography is diverse, with a predominance of Western European settlers. The population within which the research data was collected did not generally contain women of a reproductive age, though this will change within the next few years when my participants may become pregnant. However, it has also been established that women with CF possess lowered fertility rates (Edenborough, 2001; Johannesson, 2002).

1.5 Significance of the study

This study is significant because CF is not the only disease condition that is experiencing longer and better survival rates. People with chronic and non-chronic diseases such as hemophilia, HIV aids, leukemias, lymphomas and sickle cell anemias are all experiencing prolonged existence due to medical technological advancement. The results from this study may help us gain an understanding of the lived experience of people with CF and may allow us an insight into the conditions of surviving other chronic disease as well.
1.6 Methodological considerations

I found that research focussing on the psychosocial aspects of CF generally utilises quantitative standardised measures. For example Meijer, Sinnema, Bijstra, and Wolters studied adolescents\(^3\) to assess and measure psychosocial health using the following scales: Child Behaviour Check List (CBCL), Self perception Profile for Adolescents (SPPA), Matson Evaluation of Social Skills with Youngsters (MESSY), and Scale for Interpersonal Behaviour in Adolescents\(^4\) (SIG-A) (Meijer, Sinnema, Bijstra, & Wolters, 2000). Their results showed self-esteem and social skills improved with age. They concluded that older adolescents may adjust better to their chronic diseases than the younger adolescents, but were unable to explain the role of compliance and non-compliance in adjustment to their illness. They were also unable to explain why self-esteem and social skills improved with age.

Another group of researchers used the Health Related Quality of Life (HRQoL) scale to measure the impact of disease on daily functioning of CF adolescents by modifying the scale to the Cystic Fibrosis Quality of Life scale (CFQoL) (Gee, Abbott, Conway, Etherington, & Webb, 2000). These studies found statistical correlations between physical functioning and social functioning, with a \( P \) value greater than 0.001 showing that good physical functioning equates to good social functioning. They also found that the Cystic Fibrosis Quality of Life scale (CFQoL) is able to detect changes in health status. This scale is useful to predict changes in health but unable to detect what behaviour causes changes to health status. Donald, in his review of studies using the Health-Related Quality of Life Outcome scales, states that there are no simple answers as to the ‘right’ measure or ‘best design’ in detecting differences between the objective clinician’s assessment, and the subjective patient’s perspective in our complex health care system (Donald, 1997).

\(^3\) The researchers in this study used the term adolescents, whereas I have chosen, in preference the term young people.

\(^4\) See footnote 3.
The most recent study conducted by Rapoff (2006), utilising multi-assessment to measure non-adherence, suggests that the rate of adherence to medications varies widely across patient samples. This study also found that adherence to therapeutic exercises is more problematic than adherence to medications. Rapoff’s work suggests that one way to increase adherence is to involve and negotiate with patients and family so that they play a more active role in their health care (Rapoff, 1999, 2006). Whilst this research tells us what kinds of behaviour these young people are displaying in their non-adherence practice, it does not tell us how these young people think about issues of identity, disease, life and growing up and how this relates to adherence and survival.

1.61 Qualitative considerations

What distinguishes this present study from others is the realisation that trying to understand the narratives of the lived experience of individuals living with CF cannot be accomplished by bell shaped curves, means, medians and standard deviations. Therefore, the choice in my study was to move away from quantitative research, which is suitable for quantifying, measuring, categorising and specifying interventions (Creswell, 2003), but which is limited in what it can tell us about the complex conditions of people in their uniqueness or their commonality (Hollway, 1989). I am interested; rather, in giving voice to these young people to enable them tell their own stories, from their own lived experience.

Since I am particularly interested in understanding the personal and the subjective, this research involves a journey into qualitative research methods. Rather than studying rates, correlations, or frequency, I focus on the multifaceted, storied lives narrated by twenty one participants living with CF. This decision is influenced by the conviction that an examination of
participants' narratives will allow me to understand the multiple ways my participants currently constitute their engagement with their disease.

1.62 Discourse

Bruner, a psychologist, commented that the language of narrative can create for people “possible worlds” they live in and what other “possible castles” are conceivable for their futures (Bruner, 1986, p. 45). The position I am taking in this research is to question how young people living with CF build ‘possible worlds’ and ‘possible castles’, within the confines of the discursive space of CF. I have adopted the term ‘discourse’ to use in my data gathering and analysis. Historically, the ‘turn to language’ in psychology was influenced by Harre (1991) and Shotter (1993), who drew attention to the importance of meaning and appropriate methods to study language. Their influence provided the context from which interest in discourse and its analysis emerged (Parker, 1990). Within this paradigm, discourse is taken to mean a form of social practice that is believed to directly and indirectly influence the formation and development of subjectivity. I subscribe to the notion that language does more than represent a truth that exists independent of and prior to language; meanings are always multiple and shifting rather than unitary and fixed (Burman, 1991b). My approach to analysing the narratives of my participants is thus not to take their words as an account of a true world that exists prior to their telling. Rather, I am interested in the way these young people are constituted through language, and how they use language to constitute themselves as beings in the world who are living with CF. The poststructural strand of discourse analysis asserts that subjectivity is produced through multiple contradictory and unstable discourses (Widdicombe, 1995). I want to find out what implications these multiple ways of ‘meaning making’ have for how my participants think about what they do, or do not do, by way of compliance with the regime of medical interventions required of them to stay healthy. This approach allows me to examine the
multiple and contradictory discourses that are mobilised in the interviews, and to explain how things may look different depending on the speaker’s positioning, and the context, both historical and autobiographical. What is particularly relevant here is that my method allows me to explore the shifting ways of making meaning that my participants engage in.

1.63 Poststructuralist connections

To date there has been no research published specifically on poststructuralist understandings of young people living with CF. However, relevant poststructuralist studies have been published within the fields of education and psychology (e.g. Burman, 1991a; Davies, 2003; Davies & Banks, 1992; Honan, 2004; Laws & Davies, 2000; Walkerdine, 1998). What these studies have been able to do with poststructural analysis is to increase awareness of the discursive constitution of self in relation to the other. This is the understanding of subjectivity that informs my thesis. Honan suggests that it is not enough to engage in passive resistance to official documents and practices if one is interested in changing social or pedagogical practice (Honan, 2004). Davies suggests that researchers, teachers, and professional practitioners must take responsibility for examining the discursive practices that are taken for granted in institutional contexts and must ask what conditions of possibility they are creating and maintaining for themselves and their students (Davies, 2006). Laws uses poststructuralist thinking to move beyond what she calls ‘appropriate’ or institutionally approved behaviour, and shows how an analysis of discursive practices, and what holds them in place, allows her to loosen the ties of ‘teaching-as-usual’ and come to know herself and her students differently (Laws, 2004). Walkerdine demystifies the myth that girls and women perform poorly in school, thereby challenging the status quo and move beyond ‘taken-for-granted’ discourses (Walkerdine, 1989a). What these studies illustrate for me is that poststructuralist theory can similarly provide me with tools to lay
bare and deconstruct the fixed ideas about ‘illness’ and ‘wellness’ that underpin medical discourse.

My reasons for adopting a poststructuralist approach in this study include its ability to allow me to ‘trouble’ the taken-for-granted narratives of the young people living with CF. I will search for the meaning of survival these young people bring to their personal stories. The questions I asked in the interviews encouraged the interviewees to talk about their understandings based on their ‘insider knowledge’ arising from their lived experience (Maisel, Epston, & Borden, 2004; Winslade & Monk, 2001). The interviews utilise the narrative structure of personal stories.

My study explores the argument that understanding the ways in which my participants make sense of their lives and their illness is important in preventing what the medical model calls ‘treatment-related behavioural dysfunctions’, especially non-compliance. At the same time, the assumption that young people’s relationship to compliance is ‘dysfunctional’ is called into question. The interviews show how young people living with CF can discursively constitute themselves as healthy, and optimise their chance of survival. Since following the medical regime is necessary for survival, the interviews show how they accomplish the somewhat paradoxical subjectivity that allows them to regard themselves as normal and healthy and also follow a very demanding medical regime.

1.7 A review of the literature

As Cystic fibrosis (CF) is such a broad subject, a comprehensive review of the literature would be impossible, so at this stage of my thesis I have chosen to refer to literature relevant to the disease process of CF, and the psychological, social and historical implications. Contextual literature will be
referred to as needed throughout this thesis. I have taken this approach to create a backdrop, against which my readers can better understand:

a) The centrality of the medical discourse of CF, and

b) The enormous health challenge my research participants are negotiating.

1.71 Introducing my topic

Many of the studies focussing on the psychological or psychosocial aspects of CF utilise quantitative methods. For instance, an early study used the Ontario Child Health Study scale to estimate whether psychological distress exists in adolescents with chronic illness (Cadman, Boyle, Szatmari, & Offord, 1987). Very few psychosocial studies were conducted in the eighties and nineties. Since the year 2000 many more psychosocial studies have surfaced, such as the quantitative studies I have already described in 1.6, by Meijer, Sinnema, Bijstra, and Wolters (2000) and by Gee, Abbott, Conway, Etherington, & Webb (2000). Some of these studies found correlations between various scales of adolescent functioning, but the majority tended to focus on psychopathology (Mullins, Olson, & Reyes, 1991). It has been claimed that the scales used in such studies provide useful tools as potential predictors of disease outcomes (Staab et al., 1998). For instance, one study claimed that the use of the HRQoL scale is able to measure coping styles as a personal trait, called coping subscale. The coping subscales found that a negative indicator of coping was predictive of related ‘cognitive avoidance’ or ‘denial’ of their disease process (French, 1998). This study does not reveal, however, what the adolescent said to earn a score of ‘a negative indicator of coping’, and what they did or said to be labelled as having ‘cognitive avoidance’.

These studies supported the argument that the psychological problems require psychological therapy for managing treatment-related behavioural dysfunctions. Although I agreed with their conclusion that understanding the psychological problems of young people is important, I needed to understand what these young people said or did to earn the label of having
‘psychological problems’. This study is an attempt to open up a way of researching this field that has not been done before.

CF was recognised as a familial disease in the early to mid 1940’s (Howard, 1944; Warkany, 1943) and was conceptualised as a genetic disease even more recently. However, an historical perspective suggests that CF has been around as long as human existence (Casals et al., 1992). The following section introduces this research through a turn to history, in order to comprehend the connections, plays of force and strategies that have shaped the narratives of CF from its historical origins.

1.72 Brief demography and history of Cystic fibrosis

The genetic disease Cystic fibrosis (CF) is the most prevalent autosomal recessive genetic disease, affecting one in sixteen thousand to twenty five thousand Caucasian live births. (An autosomal recessive genetic disease is one in which half a trait is carried by one of the twenty two pairs of human chromosomes excluding the male and female sex hormones, with the result that both parents must carry the CF gene in order for their offspring to have CF.)

The first known written and published journal article on CF appeared in the British Medical Journal in 1901 where Bramwell described a child’s failure to thrive, due to a case of ‘pancreatic infantilism’. Bramwell documented his treatment of the child from 1901 to 1903 with a newly invented glycerine extract of pancreas. CF was called infantilism because children afflicted with this disease failed to mature physically, remaining ‘infant like’, hence the name Infantilism (Bramwell, 1903).
Figure 1 The British Medical Journal

This is an example of medical publications on pancreatic infantilism in 1904. This is included to illustrate the discourses of the period. This is the earliest reference I am able to access.
Figure 2 Case infantilism

CASE OF INFANTILISM

Case XVII.—Case of Infantilism

Patient aged 18½: chronic diarrhea of nine years' duration; complete arrest of bodily development for nine years; genitalia quite infantile; pancreatic secretion defective or completely absent; improvement in the diarrhea, gain of 8½ lbs. in weight and growth of 1½ inches in height, in the course of nine months, solely as the result of the administration of pancreatic extract.

February 5, 1902

Gentlemen, I have already shown you this little boy; but as there are a number of gentlemen present today who have not had the opportunity of seeing the case, which is one of great rarity and interest, and as we have made some further observations regarding it, which are, I think, of great importance, I take the opportunity of again bringing the patient before your notice.

Will some of you gentlemen who have not seen him before suggest what his age is?

Students. 16, 10, 13, 12, 8, 18—were suggested by different students.

Dr. B. I don’t want guesses or fancy opinions. I want you to tell me what age you think he really is. I do not think that any reasonable man looking at that boy would say he was 18, or anything like 16 years of age. He certainly does not look more than 11 or 12. I do not think anybody would put him at more than 13. Well, his actual age is 18½; he will be 19 on the 3rd of May next.

He is suffering from the condition which is termed infantilism. His growth—his bodily development—has been arrested, apparently at the age of 11 or 12; and it seems likely that, unless he is stimulated to grow by some form of treatment, it will remain arrested for years to come, possibly for the remainder of his life—we cannot tell how long. Skiagrams have been taken of the case; they show that the epiphyseal lines—which should close between the 16th and 18th years (Gray)—are not yet closed; consequently that the bones are capable of further growth. This is a most important point for prognosis.
The different parts of the body are, you will see, perfectly formed and proportioned (see Fig. 18). The genitalia are quite infantile. There is no defect in intelligence; he is very sharp and intelligent. I do not mean to say that he knows as much as most people of 19 do, or ought to do, but he is quite bright mentally. There is nothing either in his bodily conformation or mental condition indicative of sporadic crotinism. He is not the subject of inherited syphilis—his personal condition and family history enable us, I think, positively to exclude that. There is no suspicion of rickets, and there is no evidence of tubercle—unless, as I will presently point out, the diarrhoea from which he suffers is indicative of tubercular ulceration of the intestine. Sporadic crotinism, inherited syphilis, rickets, and tubercle may all retard the growth and development, and may give rise to the condition which has been termed infantilism. But none of these conditions appear to be in operation in this case. The only apparent cause which we have been able to find is chronic diarrhoea.

For the last nine years he has been suffering from diarrhoea. When he came into the hospital, he was having four, five, or six motions a day. The motions did not present any special features to the naked eye, except that they were copious, liquid, and of a yellowish brown colour. Physical examination failed to disclose any cause for the diarrhoea. The abdomen was slightly distended. The appetite was good; the stomach appeared to be quite normal; examination of the stomach contents after a test-meal showed that the normal digestive principles were present.

Since I last brought the patient before you, I have had the

These conclude the three pages of interest from the British Medical Journal.
In the *American Journal of Diseases of Children* in 1923, there was a reported case of CF, then called ‘keratomalacia’. The infant died after 18 days from malnourishment due to the inability to synthesise fat-soluble vitamin A (Wilson, 1923). Due to the complex and multi-organ involvement of CF, the disease was not identified as CF until the nineteen fifties. However, it has been suggested that the Vikings spread this genetic condition across Northern Europe during their epic conquest of Europe (details in chapter three).

Another genetic screen found that, in the South of Europe, the Phoenicians were thought to have spread CF across the Mediterranean and the Basque community north of the Mediterranean. Evidence for this historical linkage is currently being explored within the molecular genetic laboratory using molecular typing of the multiple CF mutation together with geographic maps of genetic polymorphism (Dawson & Frossard, 2000). Similarly, another study using sequence alterations and satellite markers has hypothesised that the CF gene is 30,000 to 50,000 years old, (Casals et al., 1992).

### 1.73 Some relevant information contributing to the rise in prevalence of young people surviving CF

**Cloning of the CF gene**

The CF gene, the delta F508, located on chromosome 7 on the large (q) arm of 31.2, was first unravelled by Tsui, Buchwald, Barker, Braman, Knowlton and Schumm (1985). In the following years, Riordan, Rommens, & Kerems, (1989) managed to clone the CF gene. Rommens and his colleagues then refined the gene profile (Rommens, Iannuzzi, & Kerems, 1989). The discovery of the gene for CF changed the treatment and management of this illness dramatically. Subsequently, the effective medical management of CF has exploded exponentially. Children who used to die in their primary school
years are now surviving into adulthood (CF Foundation data 1998). The American CF Foundation estimated that in their population group a third of their CF patients are now over the age of 18 years (American CF Foundation data). When the disease was first recognised in 1930, it had a mortality rate of 70% in the first year of life (Anderson, 1938), but by the year 2000, the median survival age was estimated to be 40 years old (Elborn, Shale, & Britton, 2000). Greater life expectancy is now widely reported. Phillipson (1998) correlated improved life expectancy with issues in reproductive health and pregnancy management. According to Phillipson, pregnancies in women living with CF were first reported in 1960, and by 1998 there were more than 100 pregnancies in women surviving CF in the United States alone. Another study by Jaffe & Bush estimated the life expectancy of babies with CF born in 1990 to be greater than 40 years, which represents a doubling in the last 20 years (Jaffe & Bush, 2001). These changes have lead to a consideration of the effects of aging for people living with CF. It has been found that CF adults have an increased rate of being affected by chronic diseases of aging at a younger age than the general population (Aris et al., 1998).

A similar study, which cited a three-fold increase of life expectancy internationally (Fogarty, Hubbard, & Britton, 2000), utilised the median age at death as the end point measurement. Results revealed that, although the median age at death from CF is increasing, there is significant difference in survival between countries and between genders, with women dying significantly younger than men. Kotwicki, Condra, Vermeulen, Wolf, Douglas and Farrell (2001), agreed that the CF populations are experiencing increased longevity; and Elborn described CF now as being an adult disease (Elborn, 1998). The British health system estimated an increase of 20 patients per year being transferred from the paediatrics facility to each of their three adult centres (Conway, Stableforth, & Webb, 1998). In 1999 Yankaskas and Knowles edited the first book ever to be published, dealing solely with adults living with CF. This book represents a benchmark in the 60-
year medical history of CF, and “CF has truly Grown Up!” (Yankaskas & Knowles, 1999).

This increase in life expectancy means that a myriad of new problems will emerge for maturing young people such as fertility issues, medical related problems, developmental connotations as well as psychological issues. The current research on each of these aspects will now be discussed.

1.74 Fertility issues

Women living with CF are more likely to die at a younger age than men, due to their smaller lung size compared to men, and more severe lung disease (Fogarty, Hubbard, & Britton, 2000). The common age for girls to die was in the primary school years (Britton, 1989; Rosenfeld, Davis, & FitzSimmons, 1997). During the last 20 years however, when survival rates have risen, issues of menstruation and reproduction have begun to be addressed (Lyons et al., 2006). Girls with CF are found to have later menarche, by 12-24 months, as compared to their non CF peers (Phillipson, 1998), and about 50% of young women living with CF have irregular menstruation. In view of this information, the studies suggested that only about 4% of women living with CF are able to successfully conceive and bear a live infant (Edenborough, 2001).

Young men were deemed to be infertile. The defective production of cystic fibrosis transmembrane conductance regulator (CFTR) proteins results in thickened and desiccated secretions throughout the respiratory, alimentary tracts, sweat ducts as well as the reproductive tract, thus hampering fertility in males because of the very narrow nature of the epididymis (Edenborough, 2001). The issue of questionable fertility is compounded by co-morbidity in some genetic conditions; for example, with CF its other related problem is congenital bilateral absence of the vas deferens (CBAVD). The CF gene
shares a genetic and embryological background with CBAVD (Phillipson, 1998). The association between CF and CBAVD led Crowley to state that nearly all men with CF are infertile due to a congenital bilateral absence of the vas deferens, (Crowley & Bush, 2002). They established that 98% of men with CF are infertile. Despite Sokol’s finding that the majority of men with CF have congenital bilateral absence of vas deferens, (CBAVD) associated with the cystic fibrosis transmembrane conductance regulator gene (CFTR) (Sokol, 2001), both men and women living with CF have been known to produce living offspring.

### 1.75 Medical problems

Most of the medical literature supporting innovative treatment of CF to prolong life does not refer to the fact that treatment can only be palliative, although to date there has still been no cure for CF (2010). Moreover, in surviving early death, young people living with CF now face a problematic, complex set of medical issues that will be discussed in this next section.

#### 1.751 Early death

Premature death from pulmonary complications, especially respiratory failure, pneumothorax and haemoptysis, is very common, and such complications are also significant morbidity factors (Yankaskas, Egan, & Mauro, 1999). In addition, CF adolescents acquire a form of malnutrition resulting from pancreatic insufficiency, and malabsorption syndrome, leading to early onset of chronic bone disease and osteoporosis (Edenborough, 2001).
1.752 Associated chronic disease

There are issues of chronic disease associated with CF such as:

- DIOS (distal intestinal obstruction syndrome) (Gaskin, 1999);
- Constipation (Gaskin, 1999);
- Chronic sinusitis (Stem & Jones, 1999);
- Chronic liver disease, such as stricture of the distal common-bile duct, (Gaskin et al., 1988);
- Chronic lung infection from pseudomonas aeruginosa (Ernst et al., 1999);
- Bronchiectasis and progressive lung destruction, needing continuous antibiotics use, leading to ototoxicity and nephrotoxicity (Oermann, 2000).

These chronic diseases are made worse because of their early onset, which results in the need to continuously redress the medical issues that subsequently arise. For example, although meconium ileus⁵ is a neonatal disease usually reversible at birth through surgical intervention, problems of diarrhoea, constipation and abdominal pain continue to plague the individuals (notes from paediatric emergency handbook).

1.753 Early onset diabetes

Diabetes mellitus, which is secondary to pancreatic insufficiency and biliary damage (Edenborough, F, 2001), increases the possibility of developing chronic pancreatitis, which may lead to complications resulting in early death (Cohn, 1998).

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⁵ Meconium is the first waste material present in foetal intestines. Meconium ileus is gross distension of the bowel with thickened meconium specific to infants suspected to carry the cystic fibrosis gene.
1.754 Bone disease

Early onset osteoporosis due to low bone density is universal in adults with CF due to the cumulative use of medications such as prednisone. This puts people undergoing treatment for CF at risk of fractures and severe kyphosis (Aris et al., 1998).

1.755 Family relations

Extra pyramidal effects of complex family relations associated with the chronic illness of one child can result in changes in family dynamics such as ‘triangular complications’, ‘over protection’ and ‘sibling rivalry’ to name but a few (Bowen, 1978).

It is not surprising that, given the prevalence of the above-mentioned unresolved issues, these young people often present to emergency departments with self-harm behaviours and to clinics with exacerbation of their illness through non compliance (Eddy et al., 1998). The twin issues of youth and non-compliance are very important factors to consider in the management of this chronic illness, as discussed by Abbott, Dodd, Gee, & Webb, (2001) and Fitzgerald, (2001). These researchers suggest that, for young people living with CF, the complex tasks of ‘adolescence’ are compounded by problems associated with chronic illness. These concerns for the wellbeing of young people living with CF were the inspiration for embarking on this research and trying to understand how they manage to confront a future with such overwhelming issues.

1.76 Developmental demise

Psychosocial approaches to CF and to other chronic illnesses have become more prevalent in the last decade. The 2005 issue of Clinical Child
Psychology and Psychiatry dedicated a special issue to psychosocial approaches with chronic illness. Much of the psychosocial research about young people living with CF has been undertaken in a developmental model. (Brazier & Duff, 2005; Gilchrist & Lenney, 2008; Szyndler, Towns, Van Asperen, & McKay, 2005). In my own research, while I am sympathetic to psychosocial perspectives, it has also been necessary to question the constitution of ‘adolescence’ and the construction of normative stages of development.

My participants, recruited from a major metropolitan children’s hospital in Sydney, were aged between twelve and eighteen years old and thus fall precisely into this developmental category. Adolescence has been defined as the period from onset of puberty to the completion of secondary education (Fitzgerald, 2001; Towns, 1992). Santrock identified adolescence as that transitional period between childhood and adulthood when young people find out who they are, what they are about, and where they are going (Santrock, 2004). Both Elkind and Keating describe adolescence as a turbulent developmental period, (Elkin, 1991; Keating, 1990). In the past, adolescence was touted as a time of increased conflict with parents. Perhaps due to conservative social expectations during the post war era, conflicts arose between parental expectations and young people whose focus was on independence and identity. Rice & Dolgin (2002) refer to adolescence as the period between childhood and adulthood, and they likened adolescence to a bridge over which individuals must pass before they take their place as adults. Peterson describes it as the “most exciting and dramatically” changing phase in the lifespan (Peterson, 2004, p. 320). Sigelman & Rider (2003) believe that no period of the lifespan is more important to the development of the ‘self’ than adolescence, resulting in a more differentiated ‘self concept’

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6 Many authors of the studies I have reviewed refer to the research subjects as ‘adolescents’, but in my study I have predominantly chosen to call them ‘young people’, except when the reference is to a physiological perspective on maturation. The term ‘adolescents’ has been critiqued by Wyn & White (1997, p. 53) as it ties the subject into a developmental stage and the thinking of the researcher into a developmental epistemology, thus potentially limiting the insights that the participants bring to the study.
during this phase of development. Berger states that adolescence is probably the “most challenging and complicated” period of life to describe, study or experience (Berger, 2005, p. 339). Berk (2004) contends that adolescence brings with it the capacity for abstract thinking, which opens up new realms of learning, such as the possibilities of propositional thought.

These are all examples of what Dwyer & Wyn (2001) call an outmoded type of taken-for-granted structural determinism still used to describe the adolescents of today. Dwyer and Wyn question why “studies of adolescent development … continue to analyse and interpret their lives with reference to norms of development…based on the very different life experience of the past”, which they call “a closed corpus of source material” (Dwyer & Wyn, 2001, p. 202). ‘Adolescence’ is a term used in much of the literature on CF, and it is a new and important move to question its usage. The change to ‘young people’ is not just because the data says the time frame of so-called ‘adolescence’ is different now, but a shift from the determinism of developmental thinking within developmental theories (Walkerdine, 1998). Within developmental theories there is a tendency to see a young person’s problems as intrinsic to the stage they are going through (Pfeffer, Pfeffer, & Hodson, 2003).

The work of Dwyer, Wyn and their associates (e.g. Dwyer & Wyn, 2001; Dwyer, Smith, Tyler, & Wyn, 2003) suggests that the turmoil of so-called adolescence is not inevitable and has more to do with the socio-historical period with its specific attitude to, and understanding of, ‘growing up’. This questioning of the notion of the ‘rebellious adolescent’ challenges the idea that the young people in my study will invariably rebel against medical authority and that, if they do so, it is a developmental stage. These studies of the youth of the post 1970’s generation suggest that there is a need to understand the increasing complexity in young people’s worlds today due to globalisation as well as regional and national merging of economies. They maintain that the old linear approach of youth-to-adult developmental stages
is no longer sustainable. They use the term ‘young people’ because it covers a continuum that can extend over several decades.

Wyn’s research on youth continues into the current generation. I acknowledge that the 1970’s population studied by Dwyer and Wyn (2001) may again be different to the population I draw my research data from, as my participants were born in the late 1980’s to 1990’s, nearly twenty years later. However, given the ongoing effects of neoliberalism on work, education and the family, many of these authors’ findings still ring true for my own study. For instance, they point out that the outmoded way of describing adolescents as ‘creating problems at home’ no longer applies (Dwyer, Smith, Tyler, & Wyn, 2003; Dwyer & Wyn, 2001). They describe the family as providing the most significant source of support to young people. This change in family dynamics is due to the globalisation of resources imposed on the world market. Young people are faced with higher expectations from the job market requiring both qualifications and experience. This leads to prolonged post-compulsory education resulting in young people staying in the family home for one to two decades. Pusey states that the cohort of baby boomers are continually providing for their children, who have become a life long project in what he called “intergenerational relations” (Pusey, 2007, p.14). This has resulted in people reaching across the age specific identities and overcoming barriers in order to seek a common understanding of what is good for both. This flow on effect of perceived parental support is strongly felt by the group of young people I interviewed, who claimed that their parents are valued as amongst their best friends.

1.77 Psychological, social and personal issues

This study argues that, with improved life expectancy of people living with CF, new issues associated with chronic disorders have arisen. Given that the current practice of medical management is becoming increasingly efficient
and effective due to sophisticated technology, the psychological, social and personal health management of people living with CF is still playing “catch up” with the medical regime.

Research that was conducted as long ago as between 1984 to 1986 highlighted the non-medical consequences of CF, such as the social and psychosocial problems confronting young people living with CF (Mearns, 1986; Mrazek, 1985; Passarge, Eckerland, & Stephan, 1984; Simmons et al., 1985). More recent studies including those by Blair, Cull, Freeman, (1994); Staab, Weinninger, Gerbert, (1998); Quinton, (1999); and Duff (2002), acknowledge that young people between the ages of 13 years and 18 years old are at risk of developing psychological problems in relation to their illness (Blair, Cull, & Freeman, 1994). These studies highlight the notion that psychological issues can lead to psychopathology but do not elaborate on what actions or reactions provide the ‘red flags’ for an indication of psychopathology.

However some recent studies have taken a different approach to studying the psychosocial functioning of young people living with CF. One such study by Willis, Miller and Wyn (2001) used a sociological approach to explore the mortality difference between the genders. They found that there is a difference between the attitudes of male and female young people with CF in regard to their experience of CF as a disease. The young women they interviewed expressed more negative feelings of fear and uncertainty than their male peers. The CF females, in addition, ‘embodied’ their notion of femininity by aspiring to a slender body shape, which could have implications for their morbidity (Willis, Miller, & Wyn, 2001). Whereas previous studies tended to highlight mortality using physiological functioning (Murdaugh, 1997), Willis, Miller and Wyn (2001) shed light on the differential life expectancy between young men and women living with CF by looking at gendered social practices to explain the complex issues surrounding the experience of living with CF. This research has a more socially based focus.
on how these young people negotiate the transition to adulthood. In particular they emphasise embodiment and the notion of gender, arguing that embodiment is experienced differently for men and women (Willis, Miller, & Wyn, 2001, p. 1165). The emphasis that there is a need to include a socially based explanation in examining the experience of living with CF is something that I would like to take on in my own research.

Another study by Arrington-Sanders, Yi, Tsevart, Wilmott, Myrus, and Britto (2006) also asked if there was a gendered difference in health-related quality of life of adolescents with CF. They wanted to determine whether there is a gender difference by using the Health Related Quality of Life scale (HRQoL), which is widely used in CF populations to correlate clinical outcomes and impact of disease (Arrington-Sanders et al., 2006). This group found differences in HRQoL between males and females, and reported a poorer HRQoL score for females. These scores were used to explain the higher mortality rates of females living with CF. They suggested however that further research needs to focus on the causes of the gender differences in the HRQoL scores.

This highlights my view of an urgent need for a suitable working model to assist young people living with CF in their psychological, social and personal health. In the past, the social and psychological health of people living with CF has not been seen as being as important as physical factors in their disease management (Szyndler, Towns, Van Asperen, & McKay, 2005). This could explain the smaller numbers of research articles pertaining to the CF and psychosocial health pre 1999, as compared to research in relation to the medical health of people living with CF.

A large percentage of recent research articles have been concerned with non-compliance or non-adherence to the strict medical regime required for people living with CF to stay healthy. Conrad suggested that a third of the people with chronic disease that he cared for were non-compliant with drugs,
and he observed that the rate of non-compliance increased when the regime was complex and long term (Conrad, 1985). This suggests that my participants are more likely to engage in non-compliance because their medical regime is complex as well as life long. This is one of the issues I will be concentrating on in my data analysis.

The majority of the psychological studies I found relied heavily on forms of measurement which included:

- “Children’s Hospital Locus of Control” measurement;
- “Tennessee Self Concept Scale”
- “The Goldberg Vocational Development Scale”, a disease specific coping scale, to evaluate coping-adherence relationship responses, the most popular being sets of questionnaires with coded responses, examples being; Quality of Well-Being (QWB) scale and the Quality of Life (QoL) assessment.

These studies tell us that mainstream psychological research is heavily dependent on empirical objectivity, which rests on quantification (Banister, Burman, Parker, Taylor, & Tindall, 1994). The strength of quantification is to show correlations between sets of data. But as Kotwicki et al, point out it has limitations when it comes to data interpretation (Kotwicki et al., 2001). Further the researchers found it difficult to quantify data provided by young children because children are unable to fill in the complex questionnaires required by these studies.

Several articles from interview-based studies were located. Lowton and Gabe (2003) focussed on adults with CF by exploring what ‘health’ meant to them through their lived experience and perception of the relations of health to illness. They interviewed 31 adults from a regional CF specialist centre in
South East England. Similar to my study a meeting was held between the researcher and the CF department staff to agree on eligibility criteria. A similar criterion to exclude those in extremely poor health was also decided on by this group. The respondents were also interviewed in their own homes. The interviews were subsequently transcribed and coded and grouped into categories. The coded categories established that the adults they interviewed identified four concepts relating to living with CF. Concepts that defined their health were described as either normal, controllable, distressing or a release. They found that the adults living with CF only spoke of their health rather than their illness (Lowton & Gabe, 2003). These adults used their level of health as a measure of well being when discussing other aspects of their lives. This study contributed to the understanding that people living with CF do not see themselves as being ‘sick’. This view will have implications for my own data analysis.

Another article by Graetz, Shute and Sawyer (2000), whose research was carried out in Australia, identified and investigated supportive and non-supportive behaviour from families and friends as a factor for ‘adolescents’ living with CF and their psychological adjustment. This study utilised a ‘Youth Self Report Scale’ called the (YSR) as a checklist and concluded with a probability scale, including mean and standard deviation results of supportive and non-supportive behaviours. The coded scores revealed that family members rated higher (38%) in treatment related tasks. The supportive behaviours from peers were rated lower (21%) in relation to treatments but higher (35%) in emotional acceptance of CF. I was unable to find out from this study why some forms of support were helpful and how the young people themselves made sense of what was supportive or unsupportive. Since this research was aimed at helping the young people understand their illness, I would argue that using measures of mean and

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7 At the start of my research I had meetings with the CF clinic staff to agree on criterion of eligibility, see footnote 1.
8 This group of researchers used ‘adolescent’ to describe the young people they studied.
standard deviations ratings in order to produce truth statements is a limited way of understanding human behaviour (Graetz, Shute, & Sawyer, 2000). This methodology is more useful for making general statements about populations than for generating an in-depth understanding of individual coping strategies. We know that individuals develop subjective understanding of their world through meaning making. My intent in this research is to make sense of the meanings my participants have about their world (Creswell, 2003).

A study by D’Auria, Christian, Henderson and Haynes (2000), explores the influence of peer relationships and its influence on young people’s adjustment to their illness. They concluded that encouraging and promoting peer support could be a tool towards self-adjustment (D’Auria, Christian, Henderson, & Haynes, 2000). However there were no examples as to how this can be achieved by the young people living with CF, given the current practice of discouraging peer contact due to the endemic spread of the bacteria Pseudomonas aeruginosa\(^9\) between people living with CF.

In another article the researchers developed a Chronic Illness Peer Support (ChIPS) programme to assist young people with a chronic medical condition in their adjustment to life. This study moved away from quantifying into more descriptive outcomes of the adolescents involved in the ChIPS programme (Olsson, Boyce, Tournourou, & Sawyer, 2005). The young people involved in the programme met weekly for 8 weeks with a facilitator, who encouraged dialogue and sharing of experiences of living with a chronic illness. In this model, the facilitator acts as a positive role model for participants and provides a link between participants and health professionals. The role of the facilitator is to create a safe place for these young people to discuss their experience with their peers in a similar situation. Graduates from the ChIPS programmes were encouraged to become facilitators for ongoing

\(^9\) P. Aeruginosa is a bacteria that has a great affinity with the environment of the CF lungs and once colonised it is almost impossible to eradicate
programmes. The main success of the programme was the reduction of isolation felt by all the participants, and the payoff was the building of resilience and well being verbalised by all the participants. Whereas Olsson et. al. promoted and then described young people’s agency through action research, I am more interested, in this thesis, in exploring how young people’s subjectivity and agency is constituted through their narratives.

1.8 Overview of thesis

This thesis explores the discursive positioning of young people living with CF. By examining their discursive positioning I mean to find out how they relate to CF, (Davies & Harre, 1990). My research aims to explore different facets of their relationship to compliance and non-compliance, their adjustments to the changing nature of their illness, and to understand their multifaceted tales of survival, inspiration, and aspiration. I want to understand how my participants maintain their ‘health status’ despite all odds, thus living at the edge and managing not to fall off the edge.

In this opening chapter, I have introduced my research and located its scope and significance in relation to a review of the relevant literature.

In the next chapter, I will explain the theoretical and methodological frame for the research. I will introduce the source of my epistemology and its connections to poststructuralist theory. Part one of Chapter Two describes the methodology I chose to take up and elaborates on poststructuralist thought that influenced my data analysis. Part two focusses on my method, my data collection, my participants and how my data was analysed.

Chapter Three introduces the history of Cystic fibrosis in order to set the scene and put into context the exploration, in later chapters, of the subjectivity of young people living with Cystic fibrosis. I have included a
sketch of the complicated medical treatment process for CF to contextualise how the subjectivity of my participants can be influenced by the medical discourse of this disease.

The concept of subjectivity is taken up in Chapter Four. In this chapter I outline the importance of a detailed analysis of the subjectivity of my participants within the broader tapestry of Cystic Fibrosis. As young people living with Cystic Fibrosis, my research participants are constantly being eroded as well as ‘empowered’ by medical discourse surrounding CF. The concept of subjectivity allows me to analyse how these young people are constructed, resist and take themselves up within and against the dominant medical discourse.

Chapter Five analyses the practice of normalization. Normalization, according to Foucault, is a version of regulatory power, as well as a strategy that can be taken up by individuals as self-regulation. I examine how my participants take up and demonstrate in multiple ways how they use selective medicalization in their everyday life to ‘pass as normal’.

The next analysis focusses on the process of resistance. Chapter Six takes up the theme of resistance from a poststructuralist stance to tease out the hidden and the obvious ways young people in this study use resistance to the medical discourse to live a viable life.

The last analysis explores the subjectivity of the participants using Butler’s theory of performativity. Chapter Seven remarks on the multiple ways my participants are seen to perform actions (including speech acts) that constitutes their subjectivity within and beyond the expectations imposed upon them by the CF clinic. These actions constitute a normality they desire despite living with a genetic condition.
Chapter Eight reviews the main focus of my study, which constitutes young people as agents who create spaces in their lives within the medical discourse in order to create a liveable life. The study shows how young people living with CF deploy complex practices of compliance and/or resistance to their medication regimes and to other ways they are constituted within medical discourse, in order to attain ‘normality’ and to not be ‘sick’. In this chapter, there are suggestions for future studies that may be useful to follow on from this study, in order to gain a better understanding of how to listen to, learn from, and care for this group of young people.
2 The starting point of my research

My initial plan for this research was to extend a study conducted in 2000 by Graetz, Shute and Sawyers at the Women’s and Children’s Hospital in Adelaide through the School of Psychology at Flinders University. This Adelaide research studied perceived supportive and non-supportive behaviours from families and friends and psychosocial adjustment of young people living with CF. I was particularly interested in the psychosocial adjustments section of the study. The study found a positive correlation between non-supportive behaviours from family and psychosocial maladjustment. The study pointed out that there is a need to develop a more comprehensive measure of those non-supportive behaviours that contributed to psychosocial maladjustment. I was interested in developing a better understanding of what could contribute to psychological and social maladjustment.

In my own work as a genetic counsellor working in a large public children’s hospital the predominant mode of undertaking care is based on the biomedical model. My proposed study was to conduct a survey of young people living with CF against a control group of young people without CF. The plan was to collect data about the mental health of young people living with CF and to compare this data to those without CF, matched for age and gender. The assumption was that this might assist me to identify the special needs of young people living with CF.

The initial trial run of my questionnaire with five participants (whom I knew through my clinical role) produced data, but not meaningful answers. The participants who completed the questionnaires said that they wanted another column beside the YES and NO response, because most of their answers
were neither ‘yes’ nor ‘no’ and they felt that the questionnaire did not allow them to explain in their own words what they wanted to say. My next quest was to find a research method that could allow me to look at what they wanted to say in accounts that are more detailed.

Since the purpose of this research was to understand the personal and the subjective experience of young people living with CF, my journey began with the search for locating my source of knowledge, my epistemology.

The construct of health related quality of life has been used by a number of researchers to study people living with physical and mental ill health. Staab, Wenninger, Gerbert, Rupprath, Bisson & Trettin (1998) used the Health Related Quality Of Life (HRQOL) scale to study 89 young people and adult patients with CF aged from 12-49 years old. This study found, based on low HRQOL scores, that patients with CF had ‘a depressive way of coping’ (Staab et al., 1998). I learnt from this study that their lower HRQOL scale meant that they coped less well with their disease condition. The report of this research did not elaborate on what ‘a depressive way of coping’ meant. I found another study by Powers, Gerstle and Lapey, conducted in Massachusetts in 2001 which used 24 young people with CF aged between 11 and 18 years old. This cohort is very similar in age group to the population of my study. Their parents were also included in this study. Each subject and their parents were given a questionnaire during their visit to the clinic, to be completed at home, based on the HRQOL scale. Their study found a non-correlation between the young people’s HRQOL compared to that of the parents’ self report HRQOL scale (Powers, Gerstle, & Lapey, 2001). The study argued that, in future studies, there is a need to include multiple formats with multidimensional measures to incorporate the subjective and objective impact of dysfunction associated with the illness. Both studies highlight the conceptual issues that arise in health-related quality of life research. Murdaugh (1997) comments that the instruments that have been developed to measure health related quality of life are often not sensitive.
enough to pick up perspectives of people living with a disease condition (Murdaugh, 1997).

Creswell claimed that quantitative studies look for causes, effects and outcomes, and aim to report on objective ‘reality’ rather than subjective experience (Creswell, 2003). I realize that such studies cannot assist me to understand the complexity of the experience of young people living with CF because the main goal of positivist approaches is to identify cause and effect in large populations and to establish relations amongst variables that the experimenter can control (Fox & Prilleltensky, 1997). The aim is to enable a positivist psychologist to ‘predict and control’ behaviour of subjects as a population. This is contemporary science with its hypothetico-deductive methodology, which requires a hypothesis to be formulated on the basis of a theory, and data collected independently, to test the hypothesis. Hollway (1989) analyses such research as the use of large numbers of people for statistical manipulation to produce objective knowledge, which does not address the complex uniqueness of people, or how knowledge is produced in relation to power and to specific historical conditions.

Similarly, Blaikie observed that positivist research creates assumptions about social reality, defined as a set of complex causal relations between events, and that these discrete and observable events can only be used to develop universal propositions (Blaikie, 1991). This idea is reflected in Silverman, who reported that quantitative research is reductionist, in the sense that the causes that influence outcomes need to be reduced into small, discrete sets of ideas in order to test correlations and generalise outcomes (Silverman, 2000).

My research aims to understand the specific experiences of young people living with CF, from their own point of view. It begins with individuals and the rich and complex ways in which they make sense of their lives. It looks at
discourses and narratives as a common resource that individuals draw on to construct their specific positioning in the world.

2.1 Introducing the narrative epistemology

The starting point of my epistemology rests on the assumption that narrative provides a framework for understanding young people’s talk embedded in the culture of CF, since narrative is how a person organizes their experience, or in other words, their ‘meaning making’ (Bruner, 1990). Bruner calls narrative one of the “most ubiquitous and powerful discursive forms of human communication” (Bruner, 1990, p. 77). Bruner also quoted Dewey, who proposed that language, which consists of narratives, provides us with a means of sorting out our thoughts about the world (Bruner, 1990, p 88). It has also been said that language is not just a medium for communication, rather, it hails us into existence (Winslade & Monk, 2001). Similarly, Brooks (1984) claimed that we live a life immersed in narratives, whereby we recount and reassess the meaning of our past and anticipate the outcomes of our future projects by situating ourselves at the intersections of several stories yet to be completed. Looking at narrative enables us to focus on the influence of the social on the meanings that people make of their individual life (Freedman & Combs, 1996). Further, young people living with CF ascribe meaning and constitute their experience through discourses that are appropriate, culturally available, and relevant to their particular experience. Their language will inevitably contain medical terms, for example, ‘Tobramycin nebulisers’, ‘Pep mask’ and ‘Creons’ (since these are things they encounter multiple times daily), not found in the language of young people without CF. Thus the environment of the dominant medical culture needs to be at the forefront of my awareness in interpreting the stories told by the young people in this study.
It is within the context of CF and how CF influences the ‘lived experience’ of these 21 participants that I wanted to situate the study, and to understand these young people’s talk. I began with questions about how young people made sense of their lives in living longer than their earlier predicted CF lifespan. I wanted to know how they approached their rigorous physiotherapy regimes in order to keep their lungs clear. I wanted to hear them tell ‘stories’ of what it is like to be a young person living with a life threatening illness. I do not read the interviews as transparent accounts of a reality that exists prior to the interview, but as reality-in-the-making. As Davies (1997) said, “we speak ourselves into existence through everyday talk” (Davies, 1997, p. 278). Correspondingly, Gubrium & Holstein (1997) state that refocusing our attention on story telling as a practical activity allows us to ask why the story was told in such specific ways. In the process of decoding the ‘specific ways’ of the story telling, the path for my data analysis also takes on the process of deconstruction (Derrida, 1974) as part of my journey into poststructuralist territory.

2.2 Methodology

Young people living with CF are primarily identified as ‘patients’, and as such are embedded within the doctor / patient power relationship. Poststructuralist theory rejects the assumptions of structuralism which rely on these binary pairs such as male / female, sickness / wellness. In order to ‘trouble’ these binary pairs, poststructuralist theorists use the method of deconstruction to move beyond these binary pairs and the power relations they are based on (St. Pierre, 2000). Poststructuralist theory is pertinent to my research because my plan is to move away from the sickness / wellness, doctor / patient model of the young people surviving CF, favoured by medical discourse. I wanted to think beyond the limits set by medicine, in order to look into the discursive space created by these young people living with CF.
2.21 Poststructuralist theory: a brief introduction

Poststructuralist theory emerged from the roots of structuralism, a school of thought concerned with mapping the structures of the object of enquiry. Althusser, a structuralist, introduced the concept of ‘interpellation’, where we are ‘hailed’ or called upon to become a subject of the state. The capitalist state, in his analysis, hails us to become its subjects and bear its ideology because “ideology needs subjectivity” (Mansfield, 2000, p.53). ‘Subjectivity’ refers here to the type of human being we become as we fit into the needs of the capitalist state and become its subjects. This form of ‘interpellation’ emphasises power that depends on consent rather than coercion. Gramsci called this form of arrangement ‘cultural hegemony’, where power is an ideology connected with consent and maintained by the state in a ‘civil’ society, as opposed to a ‘political’ society governed by the police and the army (Mansfield, 2000). Similarly Davies states that poststructuralist theory understands that a person is not passively socialised into the world but ‘interpellated’ into it, by actively taking up the discourses through which they are shaped (Davies & Banks, 1992).

Likewise, Saussure, (1857-1913), a structuralist who studied linguistics, influenced some poststructuralist thinking on language. Saussure insisted that there is a “pre-given, fixed structuring of language prior to its realization in speech or writing” (Weedon, 1987, p. 23). Saussure stressed that language is made of chains and signs. For Saussure, meaning is related to the place of a word in a chain of signifiers rather than to a direct correspondence between a signifier (the word) and a signified (the thing). The implication is that the meaning of signs is not intrinsic but relational. Concepts themselves are an arbitrary categorisation of our experience. In other words, with the aid of language, which is a system of signs, we have divided our world into arbitrary categories. Saussure believed in a pre-given structure of language, saying that once a signified is attached to a signifier it is fixed, the signifier (for example ‘apricot’) is a word on a page with an
abstract concept (the fruit ‘apricot’) its signified (Hollway, 1989). Structural linguistics explains how users of the same language can talk to each other, but does not explain how meanings of words can change over time (for example ‘apricot’ as a colour).

Derrida and Foucault, who came after Saussure, were referred to as ‘post’ structuralists, because they were adding to, rather than rejecting Saussure and other structuralist thinkers. Their argument was that meanings carried by language are never fixed but always open to question, always contestable. In a poststructural approach, since we can construct our world through language, we can also reconstruct and deconstruct it by the use of language. Poststructuralist theory therefore provides a radical framework for me to understand the relationship between young people living with CF and their social / medicalised world (Davies, 1990 b). The structures and processes of their particular social world are recognised as having a capacity to constrain, as well as the ability to potentiate, a liveable life with CF. Poststructuralist theory will provide me with the conceptual apparatus I need to work with my data and allow me to sieve through the ‘acts of agency’ in the research participants’ narratives.

2.22 Deconstruction

‘Deconstruction’ was a term introduced by the French philosopher Jacques Derrida. Derrida expanded upon the term ‘deconstructionism’ to emphasise the constructive power and performance of language. He introduced the concept of ‘differance’ in his theory of deconstruction by combining the verbs, ‘to differ’ and ‘to defer’. He explained that shifts in the meaning of language occur over time in a social context, and that meaning is indecisive and contestable. Meaning can always be disputed and deferred. As for Saussure, what makes language work is the difference between one signifier and all others. Because there is a difference and an absence, Derrida states,
“The structure of the sign is determined by the trace or track of that other which is forever absent” (Spivak, 1974, p. xvii). Derrida used deconstruction as a critical practice to dismantle rhetorical structures and practices held together by identity and presence. His aim was not to reject or discard these structures and practices, but to reinscribe them in another way, so that in deconstruction, knowledge is not closed but always open to reinterpretation. This is Derrida’s modification of Saussure’s initial idea that signs have no intrinsic meaning but obtain their significance from relationships to other signs in a language chain. Derrida’s emphasis on language shifting within a social context suggests that meaning is always transient and fleeting.

When St Pierre discussed the face of deconstruction, she called it “the most challenging form of poststructuralist analysis” (St. Pierre, 2000, p.479). Derrida called it a powerful tool for critiquing any structure, allowing us the freedom to rewrite the world and our subjectivity in non-linear and exciting ways (Derrida, 1974).

Deconstruction foregrounds the idea that language does not simply point to pre-existing things and ideas, but rather helps to construct things and ideas, so that things and ideas are created and maintained in everyday talk (St. Pierre, 2000). We have constructed the world through language and cultural practices. Moreover, language is always implicated in cultural practice. Deconstruction gives us a way of understanding how realities are textually constructed. Deconstructive reading positions the reader to engage in the text as well as to disrupt it. Lather describes this as “reading against the text”: that is, reading against the assumptions that shape it (Lather, 1991, p.5). This system of reading, or ‘troubling’ as Lather calls it, allows us to examine the limits of what we can think or cannot think. It allows us to challenge our cherished assumptions, as well as to demystify, categorise and question our tendency to find fixed meanings.
The poststructural concept of deconstruction provides me with a framework for my understanding of the relations between young people living with CF and their social world. Working within a postructuralist framework, I plan to use one of its many points of departure for analysis by incorporating deconstructive methods for critiquing the language structure of the young people’s narratives. This is similar to what Lather describes as ‘reading against the text’.

Since we are able to construct our world through language and cultural practices, we can also deconstruct and reconstruct it. This means that our subjectivity, and our meaning of the world, will never be fixed but will always be subjected to reconstitution and deconstruction. This theme is taken up by Butler (1995), who says that the foundations of subjectivity and reality are contingent, not absolute, and therefore open to change (Butler, 1995). It is this aspect of the tools of deconstruction that I am interested in, because it allows for the uncovering of the layers of sedimentation of the young people’s narratives in order to make sense of the constitutive process whereby they position themselves in relation to sickness and health.

In this thesis, rather than specifically taking up Derrida’s practices of deconstruction, I am influenced by how poststructuralist feminists such as Davies, St. Pierre and Lather use Derrida’s work. In the next section, I describe the feminist ‘application’, or iterations, of poststructural theory that have been most significant for my own research.

2.23 ‘Applied’ poststructuralist theory

My research draws on the works of Valerie Walkerdine and Bronwyn Davies, who are both concerned with subjectivity (Davies & Banks, 1992; Walkerdine, 1989a). Subjectivity is how a person is both constituted and self-constituting within discourse, and in particular, within my research, how my participants
give meaning to their lives within the medical discourse of CF. This means that I am concerned with how young people living with CF are ‘made subjects’ by the medical discourse and how they develop agency in relation to the medical discourse. In poststructuralist theory people are seen not to be passively shaped by social structures but rather they “actively take up as their own the discourse through which they are shaped” (Davies & Banks, 1992, p.3). Poststructuralist theory accords the possibility of agency to the subject, albeit an agency constituted through discourse. This means I will be able to make sense of how these young people become subjugated to ‘walk the walk’ and ‘talk the talk’ of young people living with a chronic genetic disease with no cure in sight, but I will also understand how they are not totally defined by this diagnosis.

Davies contends that the structures and processes of the social world have a capacity to shape, constrain and potentiate an individual’s actions. A poststructuralist analysis allows me to focus on how the participants develop their subjectivity through the available narratives and discourses (Davies, 2003).

I will draw on the concept of “positioning” to analyse how each interviewee conceives of themselves in relation to others, and to identify what position they take up in the story and how they themselves are then positioned (Davies & Harre, 1990, p. 48). By analysing the narratives told by my participants in this way, it will be possible for me to understand how they have been positioned within medical discourse, and what positions they take up in their relationship to the management of their disease process. Similarly, when Walkerdine discussed the power of patriarchy’s influence on girls’ socialisation, she argues that girls “position themselves” around the sites produced by patriarchal force. They are no longer seen as passively being imposed upon by this force, but actively take up positions available to them (Walkerdine, 1989a, p.205). In relation to my data analysis, I have chosen to take up a position within poststructuralist discourse because it will
provide me with the conceptual tools to make sense of the data I gathered. In particular, poststructuralist discourse enables me to see the multiple discourses that may be unmarked and invisible, for instance, the unspoken resistance to the medical regime, and how my participants are negotiating the slippage between being constituted by a medical regime and resisting it.

Information about the subjectivity of my participants may allow me to formulate more responsive and effective plans for caring for young people living with CF. I will be able to work with young people’s understandings and narratives to enhance the ways they can actively take up positions in relation to the medical discourse. In this view, the binary ‘compliance/-non-compliance’ does not do justice to the complex accomplishment of subjectivity by young people living with CF.

2.24 Discourse

A Discourse is a system that is comprised of thoughts, ideas, attitudes, courses of action, beliefs and practices that systematically construct subjects and the worlds of which they speak. Poststructural critique is concerned with how discourse functions, as well as where it is produced and regulated and its social effects. Bove explains that discourse is critical to poststructuralism, which sees language as organised and regulated, as well as regulating and constituting (Bove, 1990).

Foucault states that discourses are “practices which form the objects of which they speak” (Foucault, 1972, p. 49). ‘Discourse’ embodies our socially shared meanings, and defines and produces the object of our knowledge. Similarly, Parker calls discourse “a system of statements which constructs an object” (Parker, 1990, p.191). Discourses not only describe the social world but also categorise it, so bringing phenomena into sight. Discourse thus refers to a set of meanings, metaphors and statements of shared meanings.
that have their origins, not in the person’s private experience, but in the discursive culture of the community.

Foucault coined the term ‘episteme’ to describe how the ‘order of things’ is constituted. An episteme includes the organising principles, thoughts and ideas through which the world becomes classified (Danaher, Schirato, & Webb, 2000). Epistemes work by ‘speaking themselves’ through the production of ‘shared practices of meaning-making’, or what Foucault called “discursive formations” (Foucault, 1972, p. 104). They function to make speech possible, organise ideas or concepts, and produce ‘objects of knowledge’. Epistemes govern the way we can control how ideas are put into practice to regulate the conduct of others and how a topic can be reasoned and meaningfully talked about. Therefore, each discursive formation can focus on different issues as well as bringing different aspects into consideration and have different implications for what we could or should do (Burr, 2003). If communication between people is to happen, it can only happen between people who join with others around them through established shared meanings. Different discursive formations are given ‘air time’ during different periods of social/cultural influences. For example, the dominant meaning given to ‘terrorism’ today is different to the meaning of ‘terrorism’ in classical literature. The ‘discursive formation’ of the meaning of terrorism today informs us that it is ‘an axis of evil’ against which war is justified. Shotter & Lennamann reiterate that shared discursive formations give purpose to ways groups of people make meanings and respond to each other in coping with and living in their community (Shotter & Lennamann, 2002).

There are numerous discourses that constitute any object and each strives to construct it in a different way. Within discourses some statements are privileged and others can be silenced, thus constituting a discursive culture (St. Pierre, 2000). An example of statements being privileged or silenced in the discursive culture of health is the discourse on medicine. Medical
discourse is considered to be useful and valuable and is therefore privileged because it is based on the honoured discourse of science. In contrast, folk medicine and faith healers are not privileged because they work on principles that science is not competent to test or verify. This is an example of words and phrases being organised into discursive formations that position both knowledge and people in “relations of power” (Foucault, 1977, p. 206). If our knowledge of the world and our common understanding of things and events are regulated by discourses, then it is possible to say that there is an intimate relationship between discourses on the one hand and knowledge and power on the other hand.

Foucault sees power as an effect of discourse rather than a possession which can be owned by some people and not by others. Foucault says:

> What makes power hold good, what makes it accepted, is simply the fact that it doesn’t only weigh on us as a force that says no, but it traverses and produces things, it induces pleasure, forms knowledge, produces discourse. It needs to be considered as a productive network which runs through the whole social body, much more than as a negative instance whose function is repression (In Gordon, 1980, p.119)

Foucault seldom speaks of power in its own right but rather he speaks of relations of power. Within human relationships power is always present. This power is usually mobile and not fixed. It is unstable as well as reversible, so while subjects involved in this power relationship might be positioned in a hierarchy there is also a certain degree of freedom on both sides. Thus power relations also come with the possibility of resistance (St. Pierre, 2000). Individuals are able to ‘cultivate’ themselves through what Foucault calls ‘arts of existence’ that allow us to engage in as well as challenge and resist power structures. Henriques et al called this a “dual sense of appropriation -- of simultaneously appropriating and being appropriated” (Henriques, Holloway,
Unwin, Venn & Walkerdine, 1998. p.3). Sedgwick identifies the possibility of agency as “a gap in the discursive fabric of the given” (Sedgwick, 1990, p.43). Butler, on the other hand, links this dynamic to those moments in which subjects may ‘performatively’ assert their rights to a liveable life (Butler, 2004). Power relations allow us agency to position ourselves around and within discourses, maintaining, reproducing and challenging the conditions of our own lives. What is relevant to my research is the search for an understanding of how my participants living with CF cultivate their arts of existence within the power relations created by the privileging of medical discourse in the treatment of CF.

Using poststructuralist theory for understanding the narratives of the young people living with CF allows me to make visible the shifting nature of positions they can take up or not take up. The subject emerges in the act of ‘choosing’ or in the act of positioning or being positioned. Through acts of positioning or being positioned, subjects constitute themselves and are constituted (Davies, 1994). This approach also enables me to understand the living of a life that comes along with the taking up of competing discourses. Davies and Gannon (2006) pointed out that, since subjects are constituted through discourse, and since subjects are in process, we should acknowledge that both researchers and researched participants are being positioned within the research. Participants should be read not as fixed but as entering into a kaleidoscope of possibilities (Davies & Gannon, 2006). In order to develop an understanding of the multiple ways the young people living with CF position themselves and are positioned by the medical and other discourses, including the discourses I invoked in the interview, I need a system of analysis that allows me to understand the connections between subjectivity and the constitutive force of discourse.
2.25 Discourse analysis

This form of analysis is best understood as a field of research rather than a single practice because of the multiple ways discourse analysis can be read (Taylor, 2001). Thus each analysis requires an explicit theoretical framework to frame and interpret its data. As the previous section suggests, Foucault’s analysis of power and conceptualisation of discourse is central to this thesis. Discourse analysis is sometimes described as the study of ‘talk’ and ‘texts’ or the close study of language in use, Discourse analysis has also been described as a set of methods and theories for investigating language in use within social contexts (Wetherell, Taylor, & Yates S, 2001). For Foucault, however, discourse includes a range of social and cultural practices, inclusive of, but not confined to, ‘talk’ and ‘text’. Foucauldian discourse analysis shows how these practices produce, through relations of power, what comes to be known as true.

I will develop a Foucauldian discourse analytic framework to interpret the narratives of my participants. This analytic framework draws on the nature of discourse as a fluid shifting medium in which meaning is created and contested, with the subject struggling to take up a social and cultural positioning that is inevitably partial and contingent. Poststructuralist researchers cannot claim to offer objective knowledge of a ‘truth’ or ‘reality’ that exists independent of discursive formations. Poststructuralists’ focus is on the development of a multivoiced and multi-centred discourse, given that language is imperfect and fluid, and meaning is always being deferred (Banister, Burman, Parker, Taylor, & Tindall, 1994).

This study sets out to utilise a discourse analytical approach, differentiating this form of analysis from a traditional mainstream psychological orientation that focuses on realist claims to truth based on the use of scientific method.
2.3 Method: data collection

The journey of my data collection took many turns, according to my own learning along the way. I was initially informed by the theoretical methods of social constructionists because my research had its focus in psychology. ‘Social constructionist’ is a term that is used almost exclusively by psychologists who are interested in the social and the psychosocial (Burr, 2003). Similarly, Parker pointed out that there has been a resurgence of interest in social constructionist perspectives in psychology (Parker, 1998). I was attracted to social constructionist principles because, in contrast to positivist research, a social constructionist views the world with the belief that individuals actively seek understandings of their world. The focus of my inquiry is to understand the subjective meanings made by people interacting with each other in social practices. Social constructionism relocates problems away from the pathological. The positioning of the subject in this study also relocates problems away from the illness and allows the opening out of spaces around the world of young people living with CF, in order to better understand their subjective meanings.

Social constructionism maintains that knowledge of the world is constructed between people through social interactions, particularly in the medium of language, which is not a transparent way of viewing the world. This is associated with the belief that our ways of understanding are historically and culturally relative because knowledge is sustained by social process. Burman and Parker pointed out that this view stands in sharp contrast to the positivist view that language is assumed to have a direct relation to a fixed and external reality (Burman & Parker, 1993).

The social constructionist position was an attractive paradigm for me to pursue at the beginning because I was heavily influenced by a radical text by Wright and Treacher examining the social construction of medicine. These authors do not regard medicine and technical medical knowledge as a pre-given entity
separate from all other human activity. Instead they argue for the position that medicine should be seen as a highly specialised domain of social practice and discourse (Wright & Treacher, 1982). The position they took in regard to medicine was mirrored by another writer, Mishler, who was critical of the biomedical model being taken as a picture of reality rather than as a construction of reality. He argued that the biomedical model strips away the social context of illness (Mishler, 1981). Mishler used a mode of narrative enquiry, but his view of narrative was relatively unproblematised and based on shared social meaning. In contrast, a poststructural view of narrative suggests meaning is multiple, contested, contradictory and fluid.

It was during a revision of my data analysis, when I was listening to the narratives of my participants, that I realized I needed a further set of tools to make sense of their stories. I began to recognise the ongoing nature of the narratives of my participants and their ability to constitute themselves within and against the discursive practices of the medical discourse. They had the capacity to subvert the medical discourse to potentiate their individual action in positive ways (Davies, 2003). Within a social constructionist mode of analysis, I was unable to fully appreciate the elusive and creative ways the participants were talking about their lives. It was during this period of my analysis that I attended a seminar hosted by the School of Education at the University of Western Sydney, and heard speakers discussing the ideas that schools, like hospitals, use discursive practices to maintain their social structures. I learnt in the course of that day about school children who creatively subvert the system to live viable lives despite the discursive practices of schooling. I learnt that although discursive practices are constantly being created to sustain our social world, we are able change this world through a refusal of certain discourses, and the generation of new ones. I was thus introduced to the academic mode of thinking based on poststructural philosophy. I realized that using poststructuralist theory would assist me in making sense of the data that hitherto had made no sense, and enable me to better understand the stance taken by the young people living with CF, in forming their relationship with their illness.
My first question was whether I needed to collect a new set of data. However, my initial interest in examining the lived experience of my participants had led me to interviewing as the main method of data collection. I had used a semi-structured interview format that aimed to elicit open ended, vivid stories – ‘rich and thick descriptions’ - from my research participants, and had asked questions that invited the young people to position themselves in relation to the dominant discourses of CF. In doing this, I was inspired by the practice of narrative therapy (White & Epston, 1990), which I had found useful in my adjunct work as a genetic counsellor, and particularly by the practice of ‘relative influence’ questioning. Narrative therapy takes up ideas from poststructural theory as well as literary theory and ethnography, and is thus congruent with many aspects of poststructural research methodology. This meant that the data I had collected was ripe for a poststructural analysis, even though my interview questions were still partly caught up in the dominant medical discourse of illness and its ‘management’. I need to reiterate that I am a registered nurse and a genetic counsellor and had been influenced by a medical model for most of my working life. Since commencing this research I have attempted to relocate myself in relation to the medical discourse and look at my participants and their narratives from a poststructuralist stance. As I explained in an earlier chapter the nature of discourse is a fluid, shifting medium where meaning is always being created and contested depending on the social, psychological and cultural positioning my participant is caught up in. As a poststructuralist researcher I cannot lay claim to offer ‘objective knowledge’ of a truth or reality that exist independent of discursive formations. The focus is on the development of a multivoiced and multicentered discourse given that language is imperfect and fluid and meaning making is always being deferred (Banister, Burman, Parker, Taylor & Tindall 1994).

\[10\] In ‘relative influence’ questioning, the therapist asks questions, which explore the influence of the issue or problem (CF) in the person’s life, and also asks questions about the person’s influence on the ‘life’ of the problem.
With the overt turn to poststructuralist theory as a framework for my research, my focus shifted to examining the ways the young people living with CF constituted themselves around the disease of CF and the discursive power of CF in their lived experience. Butler contended that “subjection” signifies the process of becoming subordinated by power as well as the process of becoming a subject (Butler, 1997b). This idea is similar to Foucault’s understanding of power as not only forming the subject, but also providing the very conditions of its existence. Such an approach stresses the importance of exploring subjectivity in relation to CF as a disease entity, and includes analysing the cultural and discursive context to make sense of the sets of meanings and subject positions made available to my participants (Davies & Harre, 1990).

2.4 Participants: recruitment

I interviewed twenty young people recruited from the largest metropolitan children’s hospital in Australia. Demographically, this hospital is located in Sydney’s Greater West. It is centrally situated and serves the Western Sydney area as well as being readily accessible from the North via freeways motorways and link roads. Accessibility is an important feature of this hospital because it is the only hospital that provides essential specialist services to all the children as well as neonates of New South Wales. I also interviewed an older sibling of an interviewee with CF, thus bringing the sum total to twenty-one. Participation in this study was voluntary. Potential participants were told that refusal to take part in the research would in no way compromise their care.

Permission was sought from the CF team at the hospital for the display of information about the research during the Wednesday CF clinic days. This information invited people living with CF to participate. I attended all the CF
clinics on Wednesdays for four months, so I was available for parents and young people interested in the research to approach me.

This hospital was chosen due to my personal link as a staff member since 1995. At the time of the commencement of this research, I had been a member of the CF team for two years. Six months previously, I had moved departments to work in Children’s Emergency for my own professional development. Hence, all the participants and parents were known to me personally and were comfortable with my presence in the clinic. Once contact was made it was explained that all participation was private and confidential. Participants were informed at this point that they could withdraw from the study at any time without needing to offer an explanation, nor would their care at the clinic be jeopardised in any way if they withdrew. Copies of the ‘Participant Information’ sheet were made available to both parents and young people wanting to participate (see Appendix I). It was also arranged that I as sole researcher would interview the participants at their homes at a time and day convenient to the participants. I chose to interview them in their homes because I did not want a time constraint to limit their ability to talk to me. All the participants could choose to talk with me in the presence of their parents or by themselves. Some chose to speak with me in the privacy of their own rooms and others chose to speak with me in the presence of their parents. I found that, when speaking with the participants in the presence of the parents, some of the parents often offered added information left out by the participants, whilst other parents asked to speak with me when their children had finished the interview.

The participants had all been tested positive for the CF gene, the Delta F 508, and its variants. All the participants except for one were diagnosed from birth using the Newborn screening for CF, one of the several newborn screenings routinely carried out on day three after birth. The one exception was a child born in a rural area, who was tested positive for the CF gene at the age of 8 years old. The significance of early diagnosis means earlier
intervention and less damage from persistent lung infection. All the participants are white Caucasians, all born in Australia, and are between 13 and 18 years old, a mixture of 10 males and 11 females. The majority of the participants had been attending the CF clinic since birth. For most of them, the clinic has been part of their life for more than twelve years.

2.41 Procedure for consent

Young people under the age of fourteen had to have permission from their parents to participate. Prior to the interview, I explained the purpose, aim and structure of the study to both the parents and the participants. They were asked to read the ‘participant information’ sheet (see Appendix I) and clarify any points with me before putting their signature to the consent. I recruited another member of the family as a witness to the signing of the form. Copies of the participant information sheet together with the signed consent form were given to each participant whilst I kept the originals as confidential records.

At the beginning of each interview, before I turned on the audiotape, my participant, as previously mentioned, was given the choice to be interviewed alone or in the presence of his or her parents. Fifty percent chose to be interviewed by themselves and the rest chose to be interviewed in the presence of their parents. Of the twenty-one adolescents interviewed, only five parents took part in the discussion. However, more than half of the parents wanted to talk about their own experiences as well after my interview with their children. These conversations with parents were incorporated on the flip side of the tape, but were not transcribed.

2.5 Ethics

Prior to the study an ethics proposal was submitted to the ethics committee of the Area Health Service of the hospital and the University of Western
Sydney Human Ethics Committee. The study commenced after both institutions granted ethics clearance. An additional ethics approval was submitted, to both the University and the hospital, to enable me to include parents who wanted to be interviewed. Both ethics committees granted approval, since I did not intend to use this material as a part of the analysis.

2.6 Interview data

The interviews took place after school in various settings in the homes of the participants. The interviews were semi-structured and open-ended, confidential, and on a one-to-one basis, except where parents were included. All the interviews were audio taped and transcribed verbatim, half of them by myself and the other half by an independent transcriber. Field notes of the interviews were also written up after each interview. All the interviews were designed around four themes, the participants’ awareness of CF, how they coped with CF, how CF had changed them and how CF affected their lifestyle. I approached each interview with key questions, but did not stick strictly to the questions. The questions served only as a guide designed to encourage the participants to talk about the meanings and experiences of having CF. Sometimes I asked questions, which helped them, extend their answers. I created a conversational approach based on trust and rapport. Since I knew these young people well, I found that the interviews contained laughter, intimacy and bonding as though they enjoyed talking about CF to someone who understands how they feel. The interviews took over fourteen months to complete and twelve months to transcribe.

The transcripts were systematically sorted under the three headings of the interview questions. These were:

1) Questions of the influence of CF on their lives
2) Questions on the ways the adolescents manage the presence of CF
3) Questions to elicit from them what is helpful and not helpful in the current form of management.
Detailed readings and re-readings were made of the transcriptions. The names were deleted and a pseudonym placed in the transcript to ensure anonymity of participants, but age and socio economic status was left unchanged. I met most of the participants again many times in a different capacity during the next six years, some during an emergency admission to the emergency department where I worked, and others in hospital corridors, or in the wards, and sometimes during routine clinic visits.

2.7 Process of data analysis

The process of data analysis became a journey of discovery for me. It took approximately thirty-six months. During this period I had four changes of supervisors, each of whom extended me in my learning within different spheres: from Lacan’s psychoanalysis (Walkerdine, 1989b), to social constructionism (Gergen, 2001), to the realist relativist debates (Stam, 2002) (Hibberd, 2001), to postmodernism (Denzin & Lincoln, 2003), and finally poststructuralism (St. Pierre, 2000). During the process of data analysis, I was constantly alerted to the way that young people tell their stories with such economy of language. In listening and re-listening to the audiotapes, I constantly asked myself questions like,

- Why is he/she talking in this way?
- Why are some aspects of the person’s story given more ‘air time’ than others?
- How is the power of the medical model influencing the way my participants are telling their story?
2.71 Moving towards data analysis

The process of data analysis involved listening and re-listening with data interpretation constantly evolving. In the process of data assimilation, some themes emerged and others receded from importance, whilst other concepts took centre stage only to be replaced by another concept. It is like looking for the CF genetic code, where suspicious areas are amplified in sequencing, only to find that the details are now blurred, so another area of the gene map needs to be re-amplified and re-sequenced continuously. Hence, this process of data transformation helps to “find focuses so patterns start to emerge” (Miles & Huberman, 1994, p. 11). The initial decision revolved around constructing plausible ways of dealing with patterns of meaning making, from my thoughts on social construction. I had completed data analysis utilising the social constructionist mode of thinking where the main aim was to challenge the oppressive and discriminatory practices of mainstream psychology. This I felt could be done by giving voice to my participants constructing their stories without classifying their stories into ‘rights’ and ‘wrongs’. The method of data analysis using social construction had limitations, in that I found some of the data un-useable because it was inconsistent and contained ‘thin stories’. In some areas of questioning, the participants appeared to resist talking about CF, so I was unable to elicit from them the detailed answers I wanted to questions I asked. I found it difficult to escape from liberal humanist assumptions about the rational unitary subject capable of making an account of the world, as if that world could be pinned down and rendered consistent and non-contradictory.

In taking up a poststructuralist approach, the interview transcripts were approached as texts. I looked at the interview as a performance and asked what the performance accomplished (Parker, 2005). I avoided making claims about hidden thoughts or feelings, but looked at participants’ talk to find how they were being constructed through a complex range of power relations (Foucault, 1980 b). Poststructuralism proposes a shift of focus, away from
individual identity, towards relations of power within the multiple subjectivities that are available to any one person within the discursive practices of our society (Walkerdine, 1981). The relevance of this approach to my research is the possibility of understanding the multiple and constant shifting of positions that these young people living with CF take up in relation to the discursive practices of CF and the management of their disease process.

2.72 Data analysis

To scrutinize my data in poststructuralist terms, I developed three additional themes, which now serve as the organising device for the chapters that follows. These themes are ‘passing as normal’, ‘resistance’, and the self-constitution of my participants in ‘performative mode’.

The first approach to the data explores ‘passing’. What I had previously seen as a non-engagement in my questions about living with CF, I could now read as an active engagement in constituting themselves as normal. Passing was a term used by Butler, following Goffman, when Butler discussed how two black Afro-American women passed as white and how this threw light on the reproduction of race and sexuality (Butler, 1993). I borrowed Butler’s use of ‘passing’ to allow for the exploration of the discursive sets of meanings that the young people living with CF drew on to define and position themselves, and to ‘pass as normal’. Normal within this context means not having CF. I wanted to explore what is spoken and what is not spoken in relation to living with CF, and, how these ways of speaking /not speaking come to have currency in the participants’ narratives.

The second theme involved the use of Foucault’s concept of ‘resistance’. Foucault insists that subjection and resistance are constitutive of each other in the sense that subjection produces resistance (Butler, 1997). Foucault holds that power needs resistance as one of its fundamental conditions of
operation (Foucault, 1977). Exploring the way resistance worked involved examining the issues of ‘managed’ non-compliance with medication and physiotherapy. This involved looking at how young people govern themselves in their resistance against the medical regime, and what work they do towards maintaining a level of healthy functioning against the odds of becoming sick.

The third theme involved the performative self-constitution of the young people living with CF. Butler argued that gendering is a performative process (Butler, 1990). ‘Performativity’ refers to the idea that it is through the performance of gender that gender itself as a category is made real. To transfer this idea to my participants, their performativity refers to the accomplishment of themselves as a person living with CF, and as a person who is also ‘just a normal person’. This discourse of CF as a genetic disease carries with it a discursive set of ‘truths’ where ways speaking, knowing, thinking and behaving are produced. What my participants are doing is taking up performative acts of being constituted, and, often subverting, the discourse of CF in order to live viable lives. What I seek to unravel is how CF manages to ‘interpellate’ the young people living with CF and what performance the young people engage in to subvert or embrace CF. I wanted to explore the implications for my participants’ futures of this self-constitution.

2.73 Presenting my data

In order to reflect the three themes of my analysis, I have divided the analysis into three chapters. Chapter 5 will draw on Goffman’s notion of ‘passing’, as taken up by Butler, to explore what counts as normal in the talk of my participants. This will allow me to explore the shifting and complex subject positions that young people living with CF take up and juggle, in relation to being ‘stigmatised’ as having a chronic illness (Goffman, 1963). Chapter 6 explores my participants’ resistance to the binary of being healthy and having
CF. The concept of ‘resistance’ allows for the opening of a space in young people’s talk to examine the ‘risk taking’ they engaged in within their resistance to the power of the medical discourse of CF. Chapter 7 examines Butler’s concept of ‘performativity’ by considering the performances of subjectivity taken up by my participants in managing the category CF. This allows me the possibility of examining the multiple ways these young people both reinforce and subvert CF as an identity category.

In this chapter, I explored the epistemology of my research, and my initial reasons for situating the research within the focus of social constructionism. I then went on to articulate my reasons for using poststructuralism in my data analysis. In the next chapter I will cover the history of cystic fibrosis, as an important backdrop to my explorations of the modes of existence of young people living with CF. Chapter 4 will elaborate on discussions of subjectivity through an exploration of the theme of subjectivity and the various theorists who considered subjectivity important.
CHAPTER 3
NARRATIVE OF THE HISTORY OF CYSTIC FIBROSIS

Introduction

This chapter narrates the histories of CF and locates the emergence of CF as an object of concern, with reference to Foucault’s archaeology of medical gazes (Foucault, 1973). A critical history of CF is an important dimension of this thesis because it gives context to the more specific explorations of subjectivity that follow. The chapter will be divided into four sections. Part one will concentrate on the historical narratives of CF, Part two will focus on the biomedical discourse of the genetics of CF, Part three follows the discourses of disorder and treatment from 2004 to the present, and Part four discusses new therapeutic advances in the treatment of CF.

Part one

3 The Story

Once upon a time in the mists of Northern Europe lived a brave and mighty group of warriors. Their mightiness was carried by a mutation in their genes, the delta F 508 (Busch, 1990; Dawson & Frossard, 2000; Lucotte, Hazout, & De Braekeleer, 1995). These warriors came from present day Scandinavia, Denmark, Norway and Sweden, and were known as Normans, or Vikings. Their cultural influence in the Viking age was said to last from AD 800-1050. During this Age, North Western Europe was changed materially, culturally, and technologically. Life for the average person was probably a little easier; as society as a whole benefited from the trickle-down of imported wealth from trade and raw manpower. In addition the Vikings brought with them the secret of their mightiness contained in the delta F 508 mutation, which I have called the ‘warrior gene’ because of the unique properties of this mutation. (NB: Genetics of CF will be covered in section 3.3).
Meanwhile, in the great kingdom of Canaanites lived another group of ancient warriors, called the Phoenicians. They were nicknamed the ‘Sea People’ because of their great seafaring capabilities. They colonised Carthage, Sicily, North Africa, Spain, Sardinia and Southern France between 1000 – 500 BC. They set up and took control of trade in the Mediterranean, like the Vikings, they influenced the cultures, and brought wealth to the lands they invaded. They too carried a secret of their mightiness in their Genes, the CF mutation G542X (Loirat, Hazout, & Lucotte, 1997; Nunes, Gasparini, & Novelli, 1991).

During the intervening time, in the ancient Greek Kingdom lived another mighty warrior, Alexander III, who ruled during the period 336–323 BC. By the time of his death he had conquered most of Ancient Greece. His legacy and conquests ushered in centuries of Greek settlement and cultural influence over distant areas. This period was known as the Hellenistic Age and featured a combination of Greek, Middle Eastern and Indian cultures. Alexander himself was featured prominently in the history and myth of both Greek and non-Greek cultures and he was popularly known as Alexander the Great. These warriors were later thought to be carriers of the CF gene with the mutation of 3120+1G arrow A and its subset N13031K (Dork et al., 1998).

3.1 Scientific connotation of CF

3.1.1 Founder effect of genes

Cystic fibrosis has an unusually high carrier rate of 1: 2500 Caucasians (Rasho & Downes, 1995). This means that about 1 in 25 people in a Caucasian population carries half a copy of this gene with the potential to cause the disease of CF. The large numbers of people who are carriers of this gene and do not have the disease of CF are considered to be remarkably
high in genetic terms (Rasho & Downes, 1995). It is believed in genetic circles that high carrier status equates with the fact that the mutation may possess ‘founder effect’. Founder effect means that in evolutionary terms there is a selective trait, which gives greater likelihood of survival over others in the population. Some examples of ‘founder effect’ are found in African sickle cell anaemia, where the carriers who do not have the sickle cell anaemia are protected from plasmodium falciparum malaria due to their abnormal haemoglobin, which renders them immune to malaria. Similarly in South East Asia there is a condition called G6PD, (glucose 6 phosphate dehydrogenise deficiency) which also protects G6PD carriers from the South East Asian strain of malaria. The only problem with having G6PD is the inability to synthesise the sugars in alcohol, hence, these people possess a low tolerance to alcohol. If all these other carriers of genetic disease possess a protective formula, it would be interesting to find out what protective mechanism the carriers of CF acquired.

3.12 Advantages of the founder effect of the CF gene

The Vikings, the Phonecians and Alexander III’s army were able to fight in foreign lands, drink foreign waters and eat foreign foods without falling prey to gastrointestinal complaints of diarrhoea and vomiting, which has been known to weaken many a great army. In addition they were not known to lose too much sweat or salt from their systems (Quinton, 1999). In days of old, salt was a scarce commodity, so selection against salt loss was another biological advantage. Not only did they conquer the lands but they spread their genes far and wide into inhabitants of those lands they conquered. The molecular genetics that uncovered the gene encoding the CF mutation is a protein that regulates the chloride channel and is an essential component of intestinal fluid secretion. This means that carriers of the CF gene possess quite abnormal intestinal fluid composition, rendering them unlikely to
contract cholera or any diarrhoea related disease (Quinton, 1994; Trent, 2005). This is deemed to be the founder effect for CF.

In the days when the ‘warrior’ genes were spread into the conquered lands, it was spread in its haploid status (half a chromosome), because the gene pool of the conquered women did not contain any CF heterozygote (i.e. they were non CF carriers). Some infants born from warrior fathers became carriers of the CF gene but were themselves unaffected. These infants were healthy and did not succumb easily to childhood diseases. The biological selective advantage or ‘founder effect’ of these infants meant they were protected from diarrhoea (Giovanni, Devoto, & Galietta, 1989; Rodman & Zamudio, 1991), whilst their counterparts died of diarrhoea related illness like dehydration, the biggest killer of small children (Michaud, Murray, & Bloom, 2001; Moulton & Dibley, 1997; Quinton, 1994). Worldwide population data from UNICEF revealed that even today, each year more than three million children still die from diarrhoea related diseases.

During the middle Ages, many of the CF carrier infants (CF heterozygote) survived the critical infant period due to the selective advantage of their ‘founder effect’ and their numbers grew. So, it became inevitable that some CF heterozygote would partner with other CF heterozygotes and produce infants living with CF. In those days babies were delivered by village midwives, and the medieval folklore of midwives predicted death for an infant that tasted ‘salty’ when kissed (Busch, 1990). The discourse of the day was that these infants were believed to be ‘hexed’ or bewitched and were left to die. And so it came to pass that licking a newborn’s forehead crosswise became a cleansing ceremony in the ancient people’s medicinal ritual at birth (Busch, 1990).
3.2 Cystic fibrosis mutations

The CF gene was found to possess many mutations. During the last count, over 800 mutations had been sequenced by the Cystic Fibrosis Genetic Analysis Consortium (Consortium, 1994). These mutations were thought to be offshoots from the three main gene lines, the delta F 508, (the Viking’s strain) the G542X (the Phoenician’s strain) and the 3120 +1G  (arrow) (N1303K) the strain carried by people associated with Alexander The Great (Dork et al., 1998).

3.3 Sequencing of the CFTR gene

Although the medical implications of CF as a genetic disease have been well understood for almost 50 years, the gene had not yet been identified in the early 1980s because molecular methods available at the time did not have the capacity to uncover this riddle (Santis, 2000). Before 1985 the location of the CF gene in the human genome was completely unknown. It was not until late 1985, when advances in molecular biology provided powerful tools called restriction fragment linked polymorphism (RFLP), that the region where the gene may be located was documented. The method of positional cloning was used. This method locates the molecular markers (polymorphism) in order to locate the target gene. This was found to be in chromosome 7 (Tsui et al., 1985). The landmarks closest to the suspected regions were investigated section by section. This is called chromosome walking and chromosome jumping, and was invented by Francis Collins (Collins, 1992). It took a further four years in collaborative efforts between the team of Tsui in Toronto and Collins in USA to reach the long-sought CF gene (Rommens et al., 1998). The CF gene is called the CFTR gene because it codes for a protein called cystic fibrosis transmembrane conductance regulator (CFTR). The CFTR functions in regulating chloride ion transport in cell membranes to enable normal functions of epithelial cellular fluids in the exocrine regions of the body (Rasho & Downes, 1995). In persons with CF there is a deletion of
a set of protein triplet bases that is the channel through which chloride ions pass across epithelial membranes. With this deletion the CFTR function is only partially processed (Rasho & Downes, 1995) causing abnormal cellular fluids to be formed, which in turn causes functional imbalances in electrolytes in the exocrine glands, especially in the transport of chloride ions (Cl-) which is closely linked to the Sodium transport system (Quinton, Martinez, & Hopfer, 1982). Since sodium ions (Na+) transport is closely linked to salt (NaCl) transport, the electrolyte imbalances means the CF affected individuals are unable to secrete enough salt and water into their cellular fluids to dilute their mucous secretions to a normal functional consistency (Sherwood, 1993). Instead, the salt is excreted through the pores of their skin.

3.4 Foucault’s version of the medical gaze

In the ‘Birth of the Clinic’ Foucault said that throughout the Middle Ages, medicine consisted of notions that had been medicine’s basic tools as far back as the early Greek civilization (Foucault, 1973). Foucault pointed out that discourse and practices influence each other. In his analysis of the development of medical knowledge and practices in the mid 18th Century to early 19th Century, Foucault examined how anatomical practices were mutually constitutive with the development of the medical gaze (Foucault 1973; During, 1992). McNay described Foucault’s use of an archaeological method to look at texts to account for the history of medicine as the most objective phase of his writing (McNay, 1994).

Foucault divided medicine during this period into three phases. These were the ‘classificatory’ phase, ‘clinical’ phase and ‘anatomo-clinical’ phase. In this segment of Foucault’s writing he described the change from medieval to modern medicine as the shift from the ‘language of fantasy’ to a world of
‘constant visibility’, where doctors developed an apparently unprejudiced gaze (Dreyfus & Rabinow, 1983).

3.41 Classificatory stage

During the classificatory stage, the notion of the disease was seen as a series of abstract and independent typologies not localised in the human body (During, 1992). Doctors regarded each disease as having its own natural history where only the total field of disease was studied (Foucault, 1973). The patients were just vessels providing an opportunity for the disease to appear or disappear. The patients had no status or stake in the disease process within this discourse. The infants born with CF during this era were left to die because it was the disease that got the ‘air-time’ not the patient. Curative medicine had not been adopted resulting in the practice of letting the disease take its own natural path. The discourse of those days of classical medicine was that death was the end point of the disease (McNay, 1994).

3.42 Clinical phase

Foucault’s clinical phase coincides with the emergence of medical science during the period of the French revolution (During, 1992). Foucault was interested in the interrelationship between doctors and patients within the space of historical moments. This historical moment happened in 1776 when the French Royal Society of Medicine, compelled by new social and environmental pressures and discourses, had to understand the prevalence and distribution of outbreaks of epidemic diseases. This move created the conditions of possibility for diseases to be understood as events manifesting on the patient’s body (During, 1992). The gaze moved into the space of patient’s signs and symptoms and ways to control or cure it. Death was no longer considered an absolute end, but an uneven degeneration and
cessation of bodily functions, when curative medicine became the discourse. Sometimes diseases cannot be cured but are prolonged so that chronic illness became a disease and death a terminal (McNay, 1994). This change reached its peak during the revolution (During, 1992), with the formation of the 'Clinic', which replaced the old hospitals, uprooted during the revolution.

### 3.43 Anatomo-clinical phase

The 'anatomo-clinical' phase followed when doctors were able to open up bodies to penetration, through autopsies, in order to determine the nature of the disease. Vertical gaze was incorporated (McNay, 1994) and pathological anatomy gave the 'gaze' a three dimensional space. Medical symptoms in the form of seeing and saying were at the forefront of diagnosis. Foucault (1973) described this as the fundamental *spatialisation* and *verbalisation* of the pathological, as attention moved from the body’s tissues to organs and from a 'language of fantasy' to a 'world of constant visibility'. The domain of the 'careful gaze' had the power to bring the truth to light, the eyes became the 'depository and source' of medical knowledge. Physicians diagnosed illness and disease through the gaze, which became active, and penetrated into 'readable' phenomena (Foucault, 1973; During 1992). The stethoscope, medical thermometer, percussion and auscultation came into wide use (During, 1992). Society was exposed to the discourse of medicalization during this period, which brought about many changes including the development of teaching clinics and changes to the function of hospitals.

According to Foucault, this change was brought about not by new discoveries, but through social and political events. Foucault’s analysis of the development of medical knowledge was not in terms of an enlightened positivism but as a transformation of relations of visibility and spatialisation (McNay, 1994). For instance in 1776, when the Royal Society of Medicine in France wanted to prevent outbreaks of epidemics, the 'medical gaze' had to
move out into the occurrence of the epidemics and to control the environment in which these epidemics were found.

Doctors began to move out into the social space to control and understand the population’s health. They began to receive universal training and emphasis was placed on clinicians’ experience in having the knowledge of the correct way to diagnose and treat a patient. The training of doctors meant that medical knowledge became unified by an elaborate process of documentation that came to be known as modern medicine (Foucault, 1973). Modern medicine was constituted as a form of authority over its subjects, the health care practitioners and patients, who can be described “as constructed through medical discourse” (Hepworth, 1999, p.21).

3.5 Historical development of CF

The rise of genetics is thought to be located after the anatomo-clinical phase of medical discourse. Nikolas Rose has described the nineteen-century as the period where society and the “persons and activities within it [were] constituted as a site subjected to scrutiny and administration in medical terms” (Jones & Porter, 1994, p.63). This ‘site of scrutiny’ extended to differentiating the normality and pathology of the populations. Through management of the health status of the individual, calculations of ‘risk factors’, such as genetic diseases came into being. Cystic fibrosis became one of the many genetic diseases that came to be constituted through the medical discourse (Bramwell, 1903).

The medical discourse of the genetics of CF makes it possible to detect and predict the incidence and spread of the disease. The carrier rate (CF heterozygote) in a Caucasian population is found to be approximately 1 in 25, meaning that four out of every 100 Caucasians are carriers of the CF disease (Rasho & Downes, 1995). As more and more carriers of the cystic fibrosis (CF heterozygote) survived, it was inevitable that two of the carriers of the CF
heterozygote gene would partner and have children. Since each CF heterozygote holds only half of the CF gene, a child of two carriers will have a one in four chance of having CF (Hodson & Geddes, 2000).

3.51 1900 Pancreatic infantilism

As I have already stated in my introductory chapter, the earliest known medical account of CF was one described in 1595 in Leinden, the Netherlands, (Busch, 1990). In 1902 The British Medical Society held a meeting where Bramwell exhibited a patient suffering from an unknown disease, which he termed Pancreatic Infantilism. Bramwell stated that a year before in 1901, he had commenced treatment on the boy who was suffering from chronic diarrhoea. Analysis of his stools identified a deficiency of pancreatic enzymes. Bramwell believed that the absence of pancreatic enzymes caused infantilism, the failure to grow syndrome, hence this 18 year-old boy remained the size of a nine year old before treatment. Bramwell illustrated that four years after his treatment with a glycerine extract of pancreas in 1904 he was shown to have gained 22 lbs, grown 6 inches and developed secondary sex organs with a deepening of his voice. The exhibition of this boy with Infantilism sparked much interest. The study was published again in Bramwell’s own Medical Journal, Clinical Studies in the January 1903 issue.

In 1904 Rentoul, having read Bramwell’s journal and treatment, applied the same treatment to a young woman aged 18 years old whom Rentoul said ‘looked to be 9 years old’. Rentoul published his findings of her improvement in growth and the decrease in frequency of diarrhoea just four months into the treatment. The paper appeared in the British Medical Journal of 1904 (Rentoul, 1904). These were some of the first known treatments for CF, which coincides with Foucault’s version of the period of the development of modern medicine.
The medical discourse in 1901 corresponds to Foucault’s ‘clinical phase’ and the emergence of the doctor’s gaze into the fields of signs and symptoms (Foucault, 1973). The practice of exhibiting patients at clinical meetings of the Royal College of Medicine became the norm. The ‘clinical gaze’ was still a large factor of patient cure. Ethics had not entered the discourse in medicine nor had informed consent or patient privacy.

Both the young man treated by Bramwell and the young woman treated by Rentoul quoted in the journal described diarrhoea as the only commonly occurring symptoms. This would highlight that in 1904, only one of the many symptoms of CF was being detected, the ‘pancreatic insufficiency’ form. Pancreatic insufficiency means that fat-soluble essential amino acids are unavailable to these children because their DNA are unable to produce the protein for the enzyme pancrease. The lack of pancrease in the intestinal system results in malabsorption, causing growth retardation. In addition, the inability to synthesise fat, also due to lack of bile, a component of pancrease, causes the formation of ‘fatty stools’ resulting in frequency of diarrhoea.

There was only one reported case of fibrotic disease with lung involvement, in a patient who died of extreme infections of the lung very rapidly. This would illustrate that the ‘lung involvement’ form of the CF mutation was rarely detected in the early 1900’s because sufferers died rapidly soon after birth from lung infection, hypoxemia and pneumonia (the biggest cause of CF death even with today’s technologies). Infected Lung diseases were largely untreatable in the 1900’s. This was ahead of the era of antibiotics and before the stethoscope was invented, therefore, lung auscultation was not practiced and most lung infections were largely missed or undiagnosed.
In 1923, almost 20 years later, another article appeared in the *American Journal of Diseases of Children* with reports of post-mortem studies of a five-month old infant who died of failure to thrive (Wilson, 1923). The post-mortem revealed the infant to have deficiency of all the fat-soluble vitamins, as well as fibrotic pancreas and lungs, with multiple other organ changes. Wilson called this condition ‘Keratomalacia’ (Wilson, 1923). In the anatomical clinical phase, post-mortems were performed, the knife joined forces with the gaze (During, 1992), and diagnoses became more precise. Thus, although almost the same symptoms (the failure to thrive symptoms) were identified in 1904, the medical discourse almost 20 years later chose to call what was later to be known as CF by another name, Keratomalacia. Unlike the 1904 case study of pancreatic insufficiency, the infant in Wilson’s study had both pancreas and lung involvement. By this time the X-Radiation process had been discovered and X-ray images of the post-mortem showed fibrotic lungs and pancreas, which Wilson diagnosed as Keratomalacia, thinking that the much discussed ‘failure to thrive syndrome’ was not linked to his case, which contained both lung and pancreatic pathology.

In 1927, De Lange reported the case of a post-mortem study of a six and a half week old infant who died from failure to thrive. The post-mortem examination revealed that the infant had cirrhosis of the pancreas and liver, which they suspected to be caused by congenital syphilis. (Liver disease in CF was not diagnosed until the eighties.) This diagnosis was tentative because the diagnosis could not find the presence of spirochetes. In addition, the islet of Langerhans was abnormal, which would rule out syphilis completely. Even with a post-mortem, a diagnosis was not able to be made, and it was concluded that the child died of a ‘disturbance of the intra-uterine environment’ (De Lange, 1927). This was later found to be another unsuspected and undiagnosed case of a CF infant. This story highlights the medical discourse of the time, where a diagnosis was given although the findings were inconclusive. It was impossible to contract syphilis without the
presence of the spirochetes that caused it. In this instance, the child’s death was blamed on the mother, due to a ‘disturbance of the intra-uterine environment’, because the doctors of the time were unable to understand the complex multiple organ involvement of CF, which took another two decades for its discovery.

### 3.53 1930-1940 Cystic fibrosis of the pancreas

In the 1930’s, CF was known as Cystic Fibrosis of the Pancreas. During this period, Anderson published a paper highlighting that the fibrosed pancreas could be connected to another fairly common gastrointestinal complication called celiac disease (Anderson, 1938). With hindsight it became known that there was no connection between celiac disease and CF, as was later confirmed by Jeffrey, a gastroenterologist (Jeffrey, 1941).

### 3.54 Cystic bronchiectasis

In April 1940, there was a meeting of the Royal Society of Medicine where Wood opened a discussion about the concerns of the commonest form of cystic disease of the lungs, called cystic bronchiectasis. It was highlighted during this meeting that Koontz was the first person to make a serious attempt at reviewing the literature of lung disease, which was called by various names, such as

- Foetal bronchiectasis,
- Congenital cyst formation of the lungs,
- Congenital cystic malformation of the lung,
- Atelectatic bronchiectasis,
- Congenital bronchiectasis, and
- Honeycomb lung.

Wood commented that all the cystic conditions of the lungs have been confirmed by post-mortem in the infant at birth. This would illustrate that the lung involvement of CF infants was not detected until much later. Another
speaker, a physician T.H. Sellors, highly regarded by his colleagues, drew the attention of the audience to two striking features of this lung condition, the regularity and constancy of the lining of the epithelium and the erratic distribution of the supporting tissues. All the supporting tissues appeared to be fibrosed, so members at the meeting decided to uniformly call the condition ‘multiple cystic disease’ (Wood 1940). Thus in the 1940’s CF was known as multiple cystic disease.

3.55 Meconium ileus

Meconium ileus is caused by thickened meconium unable to pass down the passage of the intestines to the rectum, causing intestinal obstruction and death if not treated. (Meconium is the foetus’s first waste product, accumulated during the 40 weeks in the uterus.) In 1943, a report of a case of meconium ileus was published in the American Journal of Disease of Children. The journal stated that there had been several reported cases of meconium ileus in newborn infants, all associated with occlusions of the major pancreatic duct and consequent pancreatic fibrosis. In their findings, Kaufman and Chamberlin also discovered that the infant did not secrete pancreatic enzymes. It was concluded that the lack of pancreatic enzymes was responsible for the production of meconium ileus. There was agreement among three other physicians from 1930-1940, (Bronaugh & Lattimer, 1940) (Dodd, 1936) (Kornblith & Otani, 1929), who believed that the lack of pancreatic enzyme caused meconium ileus. During this period meconium ileus was not linked with CF as it is known today (Kaufmann & Chamberlin, 1943). It was only in the sixties that the condition meconium ileus was found to be linked to one of the malformations of CF. Since babies with CF were born with malfunction of the chloride channels, the mucous secretions in all the organs of the body system becomes thick and viscous, including the meconium in the foetus’s gastrointestinal system. Meconium ileus is found in 10-15 % of all diagnosed CF infants carrying the common delta F508 gene (Yankaskas & Knowles, 1999). Today CF infants born with meconium ileus
have a better prognosis as they are treated with surgical intervention to remove the blockage, and most of these infants survive this surgical procedure.

3.56 Fibrotic disease of the pancreas

In the year 1944, in Detroit, a physician named Howard made the link that fibrotic disease of the pancreas is a familial condition. He reviewed 120 cases of infants who suffered fibrotic disease of the pancreas and found that out of twelve families there were two reported cases in each of these families. Some of the reported cases were sets of twins. In one instance, two sets of twins from two families were reported to have ‘fibrotic disease of the pancreas’. At the death of these twins the post mortem revealed that they were all affected with fibrotic disease. This was whilst Howard was investigating multiple deaths from the same disease conditions in three families and linked this to a genetic predisposition (Howard, 1944). He called it the fibrotic disease of the pancreas, and suggested that it was a heterozygous inheritance. This has since proved to be incorrect, as CF is an autosomal recessive disorder in a single gene the CFTR gene, so it is a single gene inheritance not a heterozygous (different alleles) inheritance (Trent, 2005; Yankaskas & Knowles, 1999).

3.57 Discovery of the hormone Secretin

In 1943, after the discovery of the hormone secretin by isolating it from the intestinal mucosa, experiments to find out the pancreatic functions were made possible (Comfort, 1940). The next stage of the research was to ascertain whether the inability to secrete pancreas was due to the absence of the hormone secretin. This study was taken up by Baggenstoss’s group (1948), who did a biopsy on a 16 month-old child with fibrotic disease of the pancreas; their search for secretin was unsuccessful. They concluded that
the cause of fibrotic disease of the pancreas was due to the absence of the hormone secretin (Baggenstoss, Power, & Grindlay, 1948).

Another group of researchers, Maddock and associates decided to test the pancreatic function of children diagnosed with fibrotic disease of the pancreas. They found that by stimulating the pancreas with the hormone secretin they were unable to encourage the CF pancreas to produce the enzyme pancrease. They concluded that children with fibrotic disease of the pancreas were unable to secrete pancrease. It was the enzyme pancrease rather than the hormone secretin which caused the pancreas to become fibrosed, and therefore unable to secrete the enzyme pancrease (Hadorn, Johansen, & Anderson, 1968).

It was in 1950’s when researchers firmly concluded that the cause was the absence of pancrease. They decided to call it fibrotic disease of the pancreas (Bodian, 1953; Maddock, Farber, & Shwachman, 1943; Zeuler & Newton, 1949). However it was not known then that the inability to secrete pancrease was not the only anomaly of the congenital, genetically transmitted disease of CF (Quinton, 1984). In the early 1940’s considerations of multiple organ involvements in medicine were not known.

3.6 The war years

During the period from 1940s to early 1960s progression of CF research was slow and did not yield much new information, and not many publications were found in the literature. This could be explained by the preoccupation with the Second World War, where war efforts took up most of the available human resources.
3.61 Antibiotics development 1950-1960

After the Second World War, another very important development in antibiotics at this time changed the disease status of CF dramatically. Although one of the basic forms of antibiotics, the Penicillium notatum was discovered in 1928 by Alexander Fleming, there was not enough interest to further its development. It was over ten years later during World War II, that the large number of war casualties mounting from infections resulted in an urgent need of cure, and penicillin became available for therapeutic use (Louie & Bell, 2002). This illustrates what Foucault discussed that new developments were brought about, not by new discoveries, but through the discourses of social and political events. Foucault claims that the development of medical knowledge was not due to an enlightened positivism, but to a focus on the transformation and management of productivity of people (During, 1992). It can be inferred from the example of the development of antibiotics that although the knowledge was available for over a decade it was not utilized until there was a need for governments to control the widespread infections of soldiers returned with illnesses and war injuries. They were a potential labor force that needed to be cured to prevent the build up of soldiers holding up hospital beds and draining the public purse. It was also during WWII, that other antibiotics were discovered such as streptomycin, which reduced the death rates from tuberculosis. In addition, scientists in Japan went on to discover many more new and novel antibiotics such as the mitomycin group, and kanamycin and bleomycin in the fifties (Kiumazawa & Yagisawa, 2002)


During the period of the sixties and seventies, developments in CF research were mainly directed to understanding the difference between the mucous secretions of CF patients as opposed to non-CF patients (Chernick, Eichel, & Barbero, 1964; Johansen, Anderson, & Hadorn, 1968). Since the availability
of antibiotics and pancreatic enzymes as treatment, interest turned to assessment of the pancreatic functioning and its effects on other secretory organs such as the kidneys (Jusko, Mosovich, Gerbracht, Mattar, & Yaffe, 1975), reproductive organs (Kaplan et al., 1968) and sweat glands (Schultz, 1969; Schwarz & Sutcliffe, 1967). The early eighties saw a resurgence of interest in the genetics of CF. The next section will discuss the historical developments of genetics, leading to the cloning of the CF gene.

Part Two

Biomedical discourse

3.7 Genetic developments

A Czech monk, Gregor Mendel, who lived in a monastery, first conjured up genetics, the science of genes. (Before Mendel, parental characteristics were believed to blend in the offspring.) Mendel’s hobby consisted of breeding common garden peas (Pisum sativum) in his isolated and tranquil monastery garden. He chose peas that had contrasting characteristics such as wrinkled or rounded in shape, yellow or green strains, and tall and short varieties. Mendel’s curiosity led him to play with the different breeds by crossing the tall peas with the short varieties and the wrinkled seeds with the rounded seeds. He then crossed the yellow variety with the green variety and came up with surprising combinations of peas. He found that his random selections of peas conformed to traits of genes, which he summarised into two important laws of genetics.

- Mendel’s First Law, the law of segregation of alleles, means that genetic factors governing inherited traits segregate from one another when they are transmitted from one generation to another.
- Mendel’s Second Law, the independent assortment of different genes forming recombination types: where genetic factors for different traits segregate independently (Lewin 1997).
Mendel's first work was published in 1865, and was entirely ignored by serious scientists, since no one understood its significance at the time (Connor & Ferguson-Smith, 1997).

**Figure 4 Gregor Mendel**

*Figure 12.1* Gregor Mendel, founder of modern genetics, and the focus of his experiments: the garden pea plant (*Pisum sativum*). A flower has been sectioned to show the location of stamens (male reproductive organs) and the carpel (the female reproductive organ).
Forty years later, in 1900, two cytologists, Boveri & Sutton, recognised the significance of Mendel’s laws when they independently noticed an intriguing parallel between the way in which the hypothetical Mendelian genetic factors behaved and the distribution of real visible structures inside cells. They found that Mendelian genes occur in pairs in most tissues of the body and separated into single units in the germ cells to form fresh combinations of pairs at fertilisation (Rasho & Downes, 1995).

3.71 Molecular genetics of CF

Genetics is the study of the molecule DNA (Deoxyribonucleic acid), and in the 1960s studies to understand the genetics of CF emerged. This occurred after the publication of Watson and Crick’s book the ‘Double Helix’ in 1953, which contained the first description of the structure of the genetic code, DNA, after they unravelled the double helix, the substance of our genetic code (Watson & Crick, 1953).

In every cell of our body, in a scaled-up version, our DNA looks like a thick sewing thread; each DNA carries three billion pairs of nucleotides and can stretch up to two hundred kilometres long (Sulston & Ferry, 2003). The chemical component of DNA is similar whether you are an onion or a human being. What is different is that each specific DNA carries a code, and it is this code which transmits the instructions that dictate whether we are humans or spinach. These instructions are called genes. In all living things from amoebas to blue whales, the genes encoded by DNA are collected together into chromosomes. Every single gene we carry forms the ensemble called the genome, the entire complement of a person’s DNA. The human genome was completely sequenced in June 2000 (Sulston & Ferry, 2003).

Human beings carry 46 chromosomes, or 23 base pairs of which 22 are autosomes and one set of sex chromosomes, females with XX and males
with XY. Each of these pairs is numbered from 1 to 23, in decreasing sizes. For example, chromosome pair No. 1 is the largest, and chromosome No. 21, 22 and Y or male, no 23, are some of the smallest chromosomes in the human karyotype (see diagram below). Our closest cousins the great apes carry 23 pairs of autosomes and one of sex chromosome making it 24 base pairs. Apparently between 5-6 million years ago two of our chromosomes fused to form chromosome number 2, this is where the lines separated, making us humans and them the chimpanzees and gorillas (McConkey, 1993).

Figure 5 Diagram of the human karyotype

Specific chromosomes carry specific genetic diseases, for instance Downs syndrome, also called trisomy 21, is caused by chromosome No. 21 having more than two q (large) arms (Selikowitz, 1997). This is because chromosome 21 is called the ‘fragile’ chromosome and had the tendency to
fracture during cell division resulting in parts being pulled in the wrong direction at the segregation stage of meiosis. This causes one half of chromosome 21 to get more than its fair share of the other chromosome 21, resulting in trisomy 21, Downs syndrome.

Figure 6 Karyotype from a female with Down syndrome
During the period of the early 1980s, research moved to understanding the functional capacities of CF body fluids in an attempt to find a cure (Behm, Hagiwara, Lewiston, Quinton, & Wine, 1987). On the other side of the research scene, the geneticists insisted on a discourse that most inherited diseases contained a genetic component, and they believed it was only a matter of time for the gene to be encoded. The 1980s saw a race to find the CF gene. This was made more difficult because the chromosome causing CF was unknown. The only way out was to use a trial and error method to determine which DNA polymorphic marker will co-segregate with the known CF defect. This could only be achieved by using sophisticated computer programmes for recombination and co-segregation of sequences. Several groups were in the race to find the chromosome. It was rumoured that Williamson’s team had the gene in their sight (Quinton, 1999). But it was not until late 1985 that advances in molecular biology provided powerful tools called restriction fragment linked polymorphism (RFLP) which enabled the
localization of the region where the gene may be located. The method was called positional cloning. This was achieved by finding the molecular markers (polymorphism) to locate the target gene using linkage analysis. Because of large numbers of CF affected individuals, family material was widely available for linkage analysis. CF was found to be in chromosome 7 by a team in Toronto (Tsui et al., 1985). Although chromosome 7 was identified (Knowlton et al., 1985; White et al., 1985), there remained the race to find the site of the gene, which was still unknown, and it took another four years for it to be found (Rommens et al., 1989). The process required sequential steps of using one clone to find the next clone spanning the region until an unclonable section stops the ‘walk’ where a chromosome ‘jump’ is required to skip over to the next clonable region to start the chromosome ‘walk’ again. They had to crawl 500 kilo-bytes towards the gene (Collins, 1992; Rommens et al., 1989). In 1989 the CF gene was mapped to the long (P) arm of chromosome 7 in position 23. This was called the Cystic fibrosis transmembrane conductance regulator (CFTR) gene, consisting of 250,000 base pairs (McConkey, 1993).

With the cloning of the CF gene, there was widespread belief that a cure, or better clinical management, would soon be found leading to possibilities of gene therapy.

3.73 Consequences of cloning the CF gene

The cloning of the CF gene managed to ask more questions than it answered, because it was not clear whether the CFTR gene was a chloride (cl-) channel or a regulator. It took several years for the group led by Bear to finally show that CFTR was a chloride channel (Bear et al., 1992). The findings that it was a chloride channel explained the electrolyte regulation theory but was unable to link it to the cause of thickened mucous in the airways (Quinton, 1999). The latest understanding of the role of the CFTR gene completes a complex story related to the different types of mutation found in the phenotypic (disease) expression of the CF disease. The different
mutations explain the difference in disease severity encountered by CF individuals, with some displaying a more severe form of CF and others displaying a milder disposition (Yankaskas & Knowles, 1999). It was also found that the delta F508 is the most common mutation in around 70% of all CF affected individuals who belonged to populations originating from Northern Europe. This mutation is also associated with the most severe form of this genetic disorder (Yankaskas & Knowles, 1999).

3.74 Living longer creating changes in care

As mentioned in the introduction, the median life expectancy of people living with CF is now 40 years and within this context, quality of life is increasingly being recognized as a very important therapeutic consideration (Szyndler, Towns, Van Asperen, & McKay, 2005). Modern medicine's success in treating all forms of illness has increased the prevalence of chronic disease (Gerhardt, 1990). There were countless researches measuring the quality of life of people living with CF using a multitude of health related quality of life scales (HRQOL) (Arrington-Sanders et al., 2006). The reason for the increase in interest in using health related quality of life scale, which numbered to thousands in the last ten years, was the perceived view that it is a valid clinical indicator for measuring quality of life of chronically ill people (Van Beek, 2008). The increased life expectancy of people with illness is not unique to CF alone, but is seen in hemophilia, somatic forms of cancer, phenylketonuria, galactosaemia, beta-thalassemia, hemochromatosis and a host of other genetic conditions (Connor & Ferguson-Smith, 1997). This increase in life expectancy correlates to an increase in chronic illness, termed the failure of the success of drug treatment and technology (Gerhardt, 1990). Cystic fibrosis disorder is one of the stories of ‘failure of success’, meaning that success in treatment of a lethal disorder has turned it into a chronic condition, and is palliative, but still incurable. The quality of life of chronic
sufferers of illnesses has become an important therapeutic consideration in the delivery of health care.

There have been a number of research projects which measured the quality of life of people living with CF using health related quality of life scales (HRQOL) (Arrington-Sanders et al., 2006). There has been a sharp increase in the last ten years in the use of health related quality of life scales in medical research, with projects numbered in the thousands. Initially the development of research using quality of life scales was due to the extended survival of people with acute illness, who were formerly untreated. The approach has expanded to include the study of people living with CF, due to the perceived view that a quality of life scale is also a valid clinical indicator for measuring the quality of life of chronically ill people (Van Beek, 2008).

Part three

Discourses of disorder and treatment

3.8 CF disorder and treatment from 2004 to the present

Each year since 1990, in the United States, one thousand new cases of CF were diagnosed. In Canada, during 1995, 60% of patients were diagnosed at birth and 90% by 10 years of age. There are 3098 people with CF in Canada. The mean age of Canadians with CF is over 35 (CF Foundation data). In Australia, the newborn screen for identifying CF was introduced in 1981. All the participants in my study were diagnosed via the newborn screen and their diagnosis confirmed by 1.8 months of age. On average, ten to eleven new cases of CF will be diagnosed annually in the geographical region of my data collection. This number may increase as population numbers increase, but may not diminish due to the lack of population screening for CF carriers (M. S. Watson et al., 2004).
3.81 Current services

The current services available to young people living with CF will be organised around the following themes.

- Medication
- Regime of the clinic
- Allied health support

3.82 Medication

The survival of people living with CF is totally dependent on medication. This dependence on medication means the pharmacy in the hospital of my study has made available one pharmacist who deals specifically with the CF population. This is to enable a constant supply of vital medications to the CF population on a twenty-four hour, seven days a week basis.

3.83 Pulmonary management

Although people living with CF have many varieties of clinical manifestations, the most serious of these involves pulmonary disease since it results in 90% of all CF mortality. Bacterial infection is a property of CF lungs, and occurs very early in life. It has not been established which came first, lung inflammation or bacteria colonisation (Armstrong et al., 1995). The most common bacteria infections specific to CF are Pseudomonas aeruginosa, Staphylococcus aureus and Hemophilus influenzae, needing intensive antibiotic treatment with Tobramycin either in the inhaled form delivered via a nebuliser or the intravenous form via intravenous lines (Davis, 1999). Apart from bacterial infections, the CF airways produce thick viscous fluids, which needed to be controlled to aid adequate oxygenation. The enzyme Pulmozyme had been in use for the last decade to counter the long strands of mucous clogging the alveoli. Recently the introduction of nebulised
hypotonic saline as a nebuliser had been found to be extremely useful in
relieving pulmonary symptoms (Havasi et al., 2008).

3.84 Chloride channel remedy

The delta F508-CFTR mutation which affects 80% of the CF population is
known to have a partial chloride function, causing defective production of
mucous which lines every exocrine organ in the body. It is believed that if the
chloride channel in the CFTR could be activated, normal mucous could be
achieved. Clinical trials on the use of different pharmacologic agents such as
ibuprofen, glycerol, aminoglycoside, milrinone and xanthine, are all
undergoing phase I of clinical trials (Johnson & Knowles, 1999). No
conclusive findings had been published as of today, although clinical trials
have been undertaken for a decade.

3.9 Regime of the clinic

Individuals living with CF are required to attend yearly visits to the clinic for
their “Interval Checks”. This service is especially important for country
dwellers, whose health checks throughout the year were provided by their
country practitioner. Hence, once a year, during or around their birthdays, a
total anatomical and physiological check is provided by the clinic for the
purpose of keeping a control of the disease process. The results of these
checks are sent back to the local physicians with modifications or
adjustments to the child’s treatments as needed.

3.91 Interval checks

The interval check consists of a full day’s visit to the CF clinic in the main
metropolitan centre (for example, all children living in rural areas of New
South Wales would need to attend either one of the two the clinics in
Sydney). On this day they have their weights recorded, their lung function tested, blood taken for full blood count, electrolytes, liver function tests and glucose levels. They are also required to provide a sputum sample to check for presence of pulmonary colonisation. An annual chest X ray is done to review lung condition as a baseline comparison with that of the previous year to ascertain deviations in lung pathophysiology. The clinic gastroenterologist examines them for gut functions to disqualify early onset of distal intestinal obstructive syndrome (DIOS) which individuals living with CF are prone to, due to their thickened mucous fluids (Gaskin, 1999). It must also be noted that unlike other CF clinics there is no rostered genetic counsellor available for consultation on these clinic days. If CF is deemed a genetic disease, the services of a genetic counsellor, as proposed by Gardner and Sutherland, should be made available to people living with CF (Gardner & Sutherland, 1996). The reason a genetic counsellor is not made available in the clinic in which I did my research in is a lack of funding. Although I am an adjunct genetic counsellor in the clinic, my core duty is to co-ordinate the clinic and attendance. Genetic counselling is only offered on an ‘as-needed’ basis.

3.92 Blood collection

In the past, all CF individuals having their “Interval Checks” had to front up to the waiting room in pathology to have their blood taken for analysis. This equated to a long wait in a crowded room with the probable but unsubstantiated risk of cross infections both between CF patients and other patients and within the CF individuals. Past and present research has not agreed on the risk of person-to-person spread of Pseudomonas aeruginosa. Both Govan (2007) and Kenna’s group (2007) suggested that strict cross-infection control should be practiced to prevent person-to-person transmission (Govan, Brown, & Jones, 2007; Kenna et al., 2007). On the other hand, Schmid’s group could find no convincing evidence to support
patient segregation to prevent person-to-person transmission (Schmid et al., 2008).

In 2002, funds were made available for a blood collector to be stationed in the CF outpatient’s clinic so that blood could be speedily and efficiently collected for the ‘Interval Checks’. The added service has reduced the non-compliance of blood collection level to almost zero. (Previously, the young people were found to ‘disappear’ on their way to the pathology department.) This was an important issue to overcome since analysis of the blood provides parameters of abnormalities which may later develop into problems, yet can be corrected or controlled with early detection.

Another service added to the interval checks in 2005 is the provision of a dexta-scan (bone density scanning device) to be added to the yearly checks. This procedure enables detection of early onset osteoporosis so that timely treatment can be commenced.

3.10 Allied health support on interval check days

In addition to the medical and nursing staff, there is the added involvement of allied health personnel. One such support is the dietician, whose role is to advise the individual living with CF, and their carer, about titrating fat grams eaten against the amount of pancreatic enzyme needed to help digest the fat. Since people living with CF are deficient in pancreatic enzyme production, they are unable to synthesise fat. As fatty acids are an important component of protein synthesis, enzyme supplements have to be taken by CF individuals on a regular basis. An understanding of the fatty component of foods is essential for correct dosage of enzymes. Failure to achieve this balance can result in excessive diarrhoea leading to malnutrition.

Two physiotherapists are available to assist individuals to manage their congested airways with regular lung hygiene. Maintenance of cleared
airways is to provide adequate oxygen for essential body functions. The role of the physiotherapist is to ensure correct postural drainage positions to assist the parent in performing postural drainage on their children. This process is particularly pertinent for infants under 1 year of age since they are less mobile. Lung congestion can become a problem, leading to chronic lung infection. Children over 5 years of age are introduced to the PEP or Flutter Mask. By breathing into these devices under pressure, it has the effect of exercising the lungs and allowing strengthening of lung muscles. During these clinic visits, the physiotherapists provide guidance as to the correct techniques used on both the PEP and Flutter mask.

The social worker who is also part of the allied health provision is probably the most invisible member of the team. She is available, but she does not have a room allocated for her use. All other members of the allied health team possess a specific clinic room they operate from. As I stated in the introductory section of this study (1.3), the psychological and sociological cares of this group of young people has not been deemed of importance by the medical guardians of this disease. The way this CF team is constituted prioritised management of the medicalised component of this disease condition, and marginalised social, personal and psychological cares. Although I take up this position of critique I also know that these young people are kept alive by the medical technologies. I understand that the authority of the medical profession backed by the Australian Medical Association is a powerful discursive construct that save lives, but within their terms of reference and commitment. I have always accepted the role of the medical, but since I have learnt to read with a poststructural lense I have learnt to recognise and attempt to disrupt the medical hegemonic form.

I subscribe to the view that the social worker, who is also part of the allied health provision, is the most under-utilised member of the team due to her invisibility. She is available, but she does not have a room allocated to her use. All other members of the allied health team possess a specific clinic
room they operated from. As I stated in the introductory section of this study (1.3), the psychological and social cares of this group of young people has not been deemed of importance by the medical guardians of this disease. If a parent of young people living with CF wants to speak to the social worker, she has to be paged by a staff member. Her role is strictly confined to the provision of social services such as housing, financial needs and access to home cares. All these needs are handled by the CF practice nurse, who makes a referral to the appropriate help needed for the young people living with CF as she/he is the first line of contact for the CF family. This is probably why the social worker is hardly ever needed at the clinic visits, unless there is an acute emergency for help in providing monetary assistance during clinic days. Whilst there is a practical reason that the social worker is not often called upon, her marginality and invisibility, and her focus on practical needs also speaks of the invisibility of the sociological dimensions of CF. This illustrates why the social worker's authority is not located as part of the dominant medical discourse.

Similarly, my primary role as an ‘adjunct’ genetic counsellor in the clinic means my core duty was to run and co-ordinate the clinic visits so that the day runs smoothly with no clients or specialist needing to wait needlessly to complete the interval checks (see appendix I for details). My role has been diminished to that of the organisational rather than that of the therapeutic. The CF team decided that my role as genetic counsellor was offered on only an ‘as needed basis’. This act discursively marginalised the emotional and psychological dimension of living with CF. However I was always available on clinic days so that the parents and young people could have access to my services on tap. To date, my main involvements as a genetic counsellor has been with newly diagnosed infants with CF. This has included education on chromosomal and genetic details, and in this context I supported parents who may feel guilty about passing their genetic condition to their off-spring. I worked on deconstructing the principle of intergenerational ‘blame’, so that the burden is lifted from the parents.
The recent addition of a member from Psychiatry to the CF Team was another innovation. Although not directly involved in patient care, [the psychiatrist] is consulted on psychological issues that may arise during the “Interval Check” process as well as issues needing their specialist attention, such as patterns of depression. However since this is a newly set up position I did not see any young people being referred to him in the 12 months I was at the clinic.

3.11 Treatment centre

The setting up of a CF treatment centre in 2004 at the hospital is an example of making available medical treatments involving diagnosis of immediate problems. Hence instead of the young person living with CF having to wait until outpatient clinic day to see a CF specialist they have access to the CF treatment centre for services available every weekday. The centre provides services such as sputum collection for analysis by pathologists to diagnose for Pseudomonas infection needing antibiotic treatment. Since each CF individual is assigned to a particular CF specialist, who is the primary medical carer, it is important that each CF individual can gain access to her or his particular specialist if there is an exacerbation of the disease. In this centre, the nurse in charge is able to contact the specialist directly to examine the child for speedy treatment and timely management. It is within this centre that intravenous antibiotics can be commenced and the weeklong regime continued at home through the “Home Support” intravenous antibiotics team. Members of this team visit the children in their own home to administer the antibiotics. This service minimises the inconvenience of having to hospitalise the very young for up to a month by allowing them to be treated in their own home.

Another service provided by the centre is to enable the CF children infected with antibiotic resistant fauna, Pseudomonas Aeruginosa, in their lungs to
seek specialist attention without putting other very young people living with CF at risk, as they would do in a crowded CF outpatient clinic. The mutated form of the Pseudomonas had become resistant to the commonly used antibiotics, thus needing specialist antibiotics for treatment. This form of Pseudomonas is highly infectious but specific to individuals living with CF only. It is this form of cross infection between CF individuals that the CF team is keen to prevent. In the past, the young people living with CF were only allowed into the CF clinics at the end of clinic day when the majority of the CF individuals had gone home. The availability of the CF treatment centre has met the needs of this particular group of the CF population.

Since many of the young people living with CF possess a porta-cathe, or a central line, (semi-permanent devices for administrating intravenous medication), these devices need to be flushed monthly with heparinized saline to maintain patency. This process is also provided at the treatment Centre and minimises unnecessary visits by the CF nurse and frees her to attend to more acute calls.

Part four

New therapeutic advances of CF

3.12 Gene therapy

Since the cloning of the CF gene with its hundreds of mutations, the next progression is the development of gene therapy. CF is a single gene disorder, and gene therapy could be efficacious through the introduction of a single normal (wild-type) copy of the CFTR into the CF airways to render normal functioning. The next section will discuss the different attempts at gene therapy.
3.13 Gene transfer using adenovirus

To transport the CFTR gene into the CF airways a vessel had to be found. This was thought to be feasible by using naturally occurring viruses such as adenoviruses as vectors (vessels), to deliver the deficient gene (Moss et al., 2004). The vectors had to have several important properties, the requirements being as follows:

- Adequate carrying capacity.
- Able to withstand attacks from the immune system and not cause any inflammatory reaction.
- Safe to use in CF patients with pre-existing lung inflammation.
- Able to remain effective long enough for it to correct the disease.
- Ability to be safely administered and re-administered (Lee, Matthews, & Blair, 2005).

Adeno-associated virus was chosen because it is a non-pathogenic parvovirus that fulfilled most of the above criteria. The process involved delivering the CFTR gene to the epithelium of the airways. Unfortunately, the airway surfaces lie on the outer region of the lungs, so they are constantly being eroded away via wear and tear before the gene has a chance to become effective. Therefore, multiple doses of the gene transfer have had to be administered to keep the gene at a sufficient level of function. Research is currently working on knock out mouse models\footnote{Knock-out mouse models means laboratory bred mice with its CFTR altered, so it becomes mice carrying the CF gene thus simulating CF conditions in humans.} to experimenting on delivering the gene deeper into the vascular system. The plan is to use a suitable vector (another virus) for gene transfer. If sufficient genetic material could be delivered deeper into the anatomy, this would eliminate the need for repeated doses. It has been found in some people living with CF that undergoing repeated doses of gene transfer results in side effects, which can

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lead to inflammatory reaction causing alveolar collapse (Lassance et al., 2008).

### 3.14 Indirect gene transfer

It has been observed that defective chloride channels cause a build up of sulfation in the mucous. One of the somatic gene therapies (gene therapy at the cell level) had been to induce normal function of the CFTR gene by supplying a catalyst to reduce the build up of sulfation. The researchers used the catalyst arylsulfatase B (ASB) found naturally on chromosome 5, to stimulate the endoplasmic reticulum. This causes a chain reaction leading to a chemical reaction resulting in hydrolysis of sulfatase. Hydrolysis of sulfatase reduces the build up of sulfation in the mucous rendering normal function to the chloride channel. The end result of this research demonstrated that adding arylsulfatase B (ASB) causes the degradation of sulfated polysaccharides (a reduction in sulfation). The authors suggested that in the future there may be the possibility of correcting the function of CFTR gene defect with ASB (Bhattacharyya, Dwight, & Tobacman, 2007).

A new form of indirect gene therapy is underway to target the CF population with a process to disrupt the ‘nonsense mutation’ in the stop codon of the CFTR region. The clinical trial used PTC124, whose role is to induce ribosome function. The use of PTC124 could normalise chloride transport in the CFTR gene. This study is currently undergoing phase II of its clinical trials (Kerem et al., 2008).

### 3.15 Non-viral gene transfer

The Konstan team (2004) devised another method to deliver the CFTR (wild type) gene to CF subjects without using the adeno-virus as vectors. As they pointed out, a decade after experimenting with adenovirus as vectors, this process was unable to deliver sufficient genetic materials during one
application. There was a concern that continuous application of genetic material using adeno-virus vectors exposed the immune system to neutralising elements in the virus. In an effort to develop a non-viral gene transfer vector, the Konstan team formulated a DNA nanoparticle, which had the ability to transfer larger amounts of genetic material. Phase I of the clinical trial was conducted on 12 CF patients. The study demonstrated a partial to full restoration of the chloride channel activity in the CFTR region. Unfortunately, restoration was short-term and efficacy for use will require repeated doses of DNA nanoparticle transfer. The authors suggested that this first human trial will need fine-tuning to adjust doses and locate optimal dosing parameters (Konstan et al., 2004). The Konstan method was refined by new technologies, which enable the location of the DNA nanoparticle in the lungs. The process measures the level of gene expression by using a plasmid from the firefly luciferase gene which produces light and allows bioluminescent imaging to be tracked (Foubister, 2005). This method is undergoing further clinical trials.

3.16 Lung transplant

Lung transplantation has been practiced since the 1980s but successful heart lung transplant with a CF patient was first undertaken in 1985 in the UK. The inclusion of the heart lung transplant sounds excessive but is the preferred method. It reduces the incidence and problem associated with anastomotic airway complication because the procedure preserves the donor bronchial-coronary collateral circulation (Katloff & Zuckerman, 1996). The CF patients who suffer from progressive lung disease are often malnourished and colonised with an assortment of pathogens in their airways. This makes them bad candidates for a major operation because of the risk factor that impedes transplantation success. Retrospective studies revealed the common problems facing CF patients post-transplantation include ranking high in chronic rejection and infectious complications. Lung transplantation
to the paediatric community had a success rate of 5 out of 514 patients in the USA (Liou, Adler, Cox, & Cahill, 2007). It was concluded that parameters for lung allocation score be changed from length of wait to the clinical status of patient in order to make better use of a scarce resource (Souilamas, 2008). Unless larger numbers of the general public can be persuaded to donate their organs, transplant recipients will always outweigh donor participants (Anonymous, 2008).

New therapeutic developments for CF will continue in medical research because worldwide more than 70,000 people live with CF. This genetic disease that had followed human civilisation throughout the ages will continue to plague humankind until a cure is found.

This chapter has been marked by a tension between a scientific rendition of CF and my choice of using Foucault’s analysis of medical discourses to situate my study. Moreover, from the point of view of this thesis, these scientific developments do not only form CF as the object of the medical gaze. They also, with the rise of genetics, constitute the CF sufferer herself / himself within medical discourse. Early diagnosis - as early as birth, and the probability of predictability prior to birth - and ongoing intensive treatment are both associated with the best prognosis and with the formation of a subject tied closely to the diagnosis of CF. Thus these developments call upon an urgent need to understand how young people’s subjectivities are formed in relation to CF and how young peoples’ lives can be formed and performed in ways that maximise the possibilities of rich and viable lives and relationships for those living with CF.

My next chapter will explore the formation of the ‘subject of CF’.
CHAPTER 4
SUBJECTIVITY

The last chapter discussed the emergence and problematization of CF as a genetic disease within the technology of medicalization. This technology has given rise, in contemporary times to a strict regime of treatment which prolongs lives and alleviates the symptoms of young people living with CF. In prolonging lives; this regime also creates a regulated and pathological group of subjects with no cure in sight. In order to stay alive, individuals with CF need to subject their bodies to the power of the medical discourse and become the subject of medical power.

The focus of this research is about the subjectivity of these young people living with CF, as well as understanding how they negotiate their lived experience within the social and discursive landscape of CF. In this chapter, I will explore the concept of subjectivity and consider how it informs my data analysis. This will help me understand how my participants experience living with CF and the regimented treatment regime.

4.1 My interpretation of subjectivity

Poststructuralist theory views the individual not so much as a social construction that results in some relatively fixed end product, but as one who is constituted and reconstituted through a variety of discursive practices. Poststructuralist theory recognises the self as non unitary, but forever reconstituted through a variety of discursive practices (Davies, 2003). Poststructuralism views the structures and processes of the social world as having material force. They subject individuals but also help change and give agency, enabling individual action. My aim is to explore the concept of
subjectivity within poststructural theory and use this concept to help analyse my interview data.

As I mentioned in my methodology chapter, the concept of subjectivity that is most useful to my research draws on the works of Valerie Walkerdine and Bronwyn Davies (Davies & Banks, 1992; Walkerdine, 1989). Walkerdine states,

“I want to refer to the ways in which issues of subjectivity have become increasingly important in research in which I am involved….“ (Walkerdine, 1997, p.58)

Subjectivity is different from the concept of identity because subjectivity is understood as being made possible through the discourses made relevant in the individual’s life during any particular period of history (Davies, 1994). Our subjectivity is a mixture of the life histories of our ‘being in the world’ and how these are played out, as well as how, in the telling, some discourses are given more ‘airtime’ than others in the relations of power we are exposed to (Foucault, 1979). Hollway states that subjectivity cannot be replaced by any of the terms, ‘individual’, ‘self’ or ‘identity’. Subjectivity refers to our individuality, our self awareness and the multiple and creative ways we position ourselves in relation to the discourse and practices in use at the period of our cultural history (Hollway, 1989). Different discourses are taken up during different times in our cultural history, which favor some discourses over others, thereby giving rise to different forms of the subject /subjectivity as well.

4.2 Theoretical implications of subjectivity

This research examines subjectivity as it is constituted through the medical discourses related to CF. Medical discourse, according to Parker, contains the positions of those who offer treatment through their medical knowledge, and the positions offered and taken up by the less knowledgeable ‘patients’,
in this case, young people living with CF (Parker, 1992). Medical discourse in this study includes ways of talking, thinking and acting. Medical discourse incorporates sustained, particularized, and local meaning systems. These are the discursive practices of the CF clinic, and the discursive formation of CF as a genetic disease. The objective of my analysis lies in seeing the detailed ways in which the subjectivity of my participants is played out through their personal experience of being young people living with CF, who take up subject positions made available to them through medical discourse.

Subject positions, according to Burr, are made available to us through our personal experience in relation to other people within discourse.

We have available to us a particular, limited set of concepts, images, metaphors, ways of speaking, self-narratives and so on that we take on as our own. This entails … an emotional commitment on our part to the categories of person to which we are allocated and see ourselves as belonging … Our sense of who we are and what it is therefore possible and not possible for us to do, what it is right and appropriate for us to do, and what it is wrong and inappropriate for us to do, all derive from our occupation of subject positions within discourse (Burr, 2003, p119).

The concept of positioning within different discourses allows us a way of looking at subjectivity in terms of how people are subjected to different discourses and how their subjectivity is negotiated in interpersonal life. Walkerdine discusses how as individuals we are constantly being subjected to an interplay of different discourses, each with its own structure of obligations, rights and possibilities for action, and each carrying its own brand of identity and power relations (Walkerdine, 1981). Such power relations are not only found in doctor and patient relations in hospitals but also in other institutions, for instance, in schools, where teachers and children play out the
prevailing discourses in every social interaction. Positions in discourse are seen by Davies and Harre as providing us with the choice to take up a position in a braided story line, for example when we take up a subject position in discourse such as nurse, teacher or father, then we have a commitment on our part to the category of person we take up (Davies & Harre, 1990). This implies that we have a degree of agency in taking up a subject position in discourse or for that matter in resisting it, although resistance is not always easy or beneficial. For instance, it could be not only socially but also physically harmful if we were to ‘reject’ the subject position of ‘patient’ by refusing treatment, as this could lead not only to a label of non-compliance, but also to bad health or even death.

4.3 Implications of subjectivity, in relation to Humanistic Psychology

‘Subjectivity’ is also a concept that humanism uses to explain the world we live in (St. Pierre, 2000). I therefore need to distinguish the poststructuralist use of ‘subjectivity’ from the humanist usage. I do not intend to set up a binary opposition between the two because they are not opposite to each other, but rather, situated in different discourses (Davies, 1997).

The humanistic discourse sees the individual as the agent of social phenomena and productions, including knowledge production. Hollway defines the humanist position as focussed on the ‘individual’. She states that “The idea of a core individual, an essence prior to socialization, is central to this model” (Hollway, 1989, p. 27).

Change can only be initiated by the individual and depends on the individual’s personal choice. This positioning of the individual is called ‘agency determinism’ (Hollway, 1989, p.10). In this view, change is largely dependent on the individual’s choice to ‘self actualise’. Maslow, one of the founding fathers of humanistic psychology, hypothesised that human behaviour is motivated by a series of competing needs and that self-
actualisation is situated at the peak of the ‘human hierarchy of needs’ (Maslow, 1954). Maslow’s humanistic theory was further developed by Carl Rogers, who postulated that the organism is the sum total of the self, called the ‘self-concept’. This psychological term ‘self-concept’ is an organised pattern of one’s own characteristics that is believed to be constant over time. Humanistic psychology asserts that our ‘self-concept’ is a relatively static entity, and remains stable over most of our lifetime (Smith, 1998). Rogers believes that ‘self-actualisation’ provides the impetus for all behaviour. Rogers states that ‘actualisation’ is an inborn tendency of the organism to realize its intrinsic potential to grow and improve and strive for self-enhancement. However, Smith suggests that self-actualisation is an attempt to maintain a consistent self-concept that fulfils the ‘conditions of worth’ established by society (Smith, 1998). Humanistic psychology constructs humans as uniquely different from all other animals in that people are generally good and striving to become better through ‘self actualisation’ (Smith, 1998).

The Humanist tends to view the individual as the sole agent of all productions and social phenomenon including knowledge. The humanist notion of subjectivity is that of one core individual whose feelings are ultimately a product of nature and not of culture. While social and cultural factors are acknowledged, these are seen as shaping a subjectivity that belongs to and is located in the individual, as their ‘nature’. Within this system, only the individual and the individual’s choice (Hollway, 1989) can initiate change. Identity arises from early socialisation and these values are internalised in the individual. Humanism is a dominant discourse of psychology and its influence has been pervasive. It is the air we breathe, the language we speak and influences everything we do in our past and our future; we cannot escape humanism (St. Pierre, 2000). Therefore poststructuralism is not planning to escape humanism, but work alongside it to understand subjectivity and its functions. It is not intending to set up a binary between the humanist subject and the ‘anti-humanist subject’ (Davies, 1997).
The bridge straddling humanism and poststructuralism comes from the structuralist, who holds the Marxist view that for any change to occur one must change the structures governing the people, for example, the social and political structures. Within this view lay the tussle of the dualistic, the individual versus the social. In order to transcend this dualism the social constructionist stance rejected both determinism and structuralist stances and adopted one concerned with language-‘ing’ the ‘self’ and the ‘subject’. The ensemble of a social constructionist’s ‘subjectivity’ is thus a combination of the individual and the social. Social constructionists embrace the position that the ‘selfhood’ that we acquire represents the language we develop and the structuring of our experiences from influences of our culture, both socially, historically and geographically (Burr, 2003, p. 106).

Poststructuralists also understand that the individual is not a fixed or given entity but rather is a production of social regulation and historically specific practices (Henriques, Holloway, Unwin, Venn, & Walkerdine, 1998). However, whereas social constructionists see identity as socially constructed, poststructuralists attempt to dissolve the binary opposition of social and individual through a concept of subjectivity. Thus, while social constructualism helped me to shape a radical stance in the initial stages of my thesis project, poststructural theory has provided the tools to consider subjectivity in its specific movements and moments, which Davies (2006) has called mo(ve)ments.

The subjectivity of young people living with CF can be seen to be a product of CF practices and CF discourses, which work through them, and influence the positions they take up. Thus, I need to be reflexively aware of the pervasive influence of the CF discourse when analysing my data.
4.4 Theorists of subjectivity

During the second half of the twentieth century, theories of subjectivity or theories of the ‘self’ became central in defining issues of the ‘postmodern’ culture (Mansfield, 2000). ‘Selfhood’ has become marketable, but it cannot function in isolation and is always linked to society, other subjects and prevailing discourses. In this section of my thesis, I have selected several theorists whose theories of subjectivity are relevant to my research.

4.41 Foucault and subjectivity

According to Mansfield, theories of subjectivity that dominated the second half of the twentieth century fall into two broad categories (Mansfield, 2000). The first is in the work of Jacques Lacan who attempted to define the nature or structure of the subject and its ‘truth’. The second is the work of Nietzsche and Foucault who see subjectivity as the product of culture and power. My interest lies in exploring ways in which my participants take up, as their own, aspects of the discursive power of CF. Therefore I have primarily chosen to use theories of subjectivity expounded by Nietzsche and, in particular, Foucault, although my study also touches upon a poststructural psychoanalytic account of subjectivity, through the work of Judith Butler. This section of the chapter explores Foucault’s view on the subject and subjectivity.

Foucault’s main ‘oeuvre’ is against the notion that there is a rational autonomous free subject who is fully self-reflexive and unified, the subject of Humanism as proposed by Rousseau (Mansfield, 2000). Foucault argues that the subject is a by-product of discursive formations, so in Foucault’s view; to be a subject is to be subjected (McNay, 1994). In his earlier work, Foucault was interested in governmentality and the development of institutional practices, which categorised the mad as inhuman and deprived individuals of their freedom. From the beginning, a Foucauldian analysis of subjectivity was located in hospitals, where discourse positions patients as
bodies that medical practice can ‘inscribe’. Medical practice gives power to
the doctors to prescribe treatment for the patients as they see fit. Foucault
developed the notion of ‘docile bodies’, to analyse the way one segment of
the population is able to regulate other ‘bodies’. Foucault views the medical
gaze as a form of governmentality to police the nation’s health.

This form of policing is interested in the quality of the labour force as an
apparatus of production. Examples of controlling bodies can be found in
institutions such as schools, with teachers controlling children; the army, with
major generals controlling the soldiers; hospitals with doctors and patients,
and mental health facilities with psychiatrists and patients. These institutions
reinforce capitalist values and as Mansfield states, induce in us ‘the right
degree of docility and fatalism’ to make us useful citizens and subjects
(Mansfield, 2000, p.53).

Foucault sees that power operates in multiple ways to produce discourses
and subjects. For Foucault repression and prohibition are only one mode of
power. Modern power is decentralised, fluid and always open to resistance.
Foucault maintained that modern power operates primarily in a productive
rather than a repressive way, although tending towards domination. Power,
in this view, is never simply negative, since it produces social possibilities
and subjective capacities, as well as governing populations and dividing
people into categories of normal and abnormal / deviant. This is what
Foucault means by the ‘positivity’ of power.

Translating this to my research, the paediatric physician in a medical
discourse is seen as someone with the power to delegate and control the
discourses of treatment in relation to young people living with CF. This form
of power is particularly visible when the refusal of treatment is taken up by
the young people in their tussle to be free. This action is frowned upon and is
deemed non-adherence by the physicians. However, from a Foucauldian
analytic of power, I read the actions of these young people as resistance to
dominant power. This theme will be explored in one of my data analysis chapters.

McNay discusses Foucault’s later thoughts on power, where power is defined both as an objectivising and a subjectivising force (McNay, 1994). Foucault’s fundamental aim is the opening up of a space in which to think ‘difference’ or ‘otherness’ through the critique of rationality. Foucault developed the idea that the subject only came into existence through the interplay of power and language, where one group of people tries to constitute another through power and knowledge. So, the subject becomes constituted through the double work of power and knowledge. For example, prison, schools, and factories function on a day-to-day basis to produce and govern our subjectivity. The subjectivity of both the citizen in the street and the prisoner are constantly being measured and analysed according to ‘norms’. We have come to accept files of us being kept in hospitals, schools, banks, and universities as normal and a necessary part of life, rather than as forms of subjection. In his late work, Foucault focuses on how individuals participate in their own subjectification, and on how an ‘art of existence’ might be possible within and against dominant discourse.

4.42 Walkerdine, Henriques, Hollway, Unwin, Venn and subjectivity

Henriques, Hollway, Unwin, Venn, & Walkerdine describe subjectivity as the conditions of being a subject. That is, the subject is always changing, dynamic and multiple, because it is always positioned in relation to the discourses and practices produced around it, the conditions that influence the subject (Henriques, Holloway, Unwin, Venn, & Walkerdine, 1998). They argue, following Foucault, that power is not a property but a relationship, because they hold the view that power works through the subject’s actions in practices that are discursive. Therefore, the subject is deemed to be an effect of a production caught up in a web of social practices, discourses and
subjectivity (Henriques, Holloway, Unwin, Venn, & Walkerdine, 1998). They illustrate this point by discussing the different categories of ‘woman’, which correspond to a multiplicity of subjectivities such as wives, mothers and consumers, where each can take on different subject positions, and each plays out different power relations. These power relations are played out in welfare practices that differently favour ‘single women’, ‘mothers’ and ‘married women’. As Walkerdine states:

The mother was first of all to be taken out of the gin palaces and streets and made responsible for a clean, hygienic and disease free home and later to become responsible for the psychic health and emotional and cognitive development of her children… (Walkerdine, 1997p. 108)

This theme is illustrated in the subjugation of women by reinforcing their role as mothers, sometimes by the privileging of mothers and tying them to positions which give women who have children more power than women without children. The discourse of ‘motherhood’ creates contradictions in subject positions, which Henriques, Hollway, Unwin, Venn & Walkerdine refer to as ‘contradictory subjectivities’. The condition of ‘contradictory subjectivities’ is caused by the experience of having more or less power in different social practices due to the triadic influences of power-knowledge-subject each juggling for positions (Henriques, Holloway, Unwin, Venn, & Walkerdine, 1998). How this theory relates to my research is the understanding that, within the CF clinic, there also exist the triadic influences of power-knowledge-subject. These issues are played out between doctors, nurses, parents, social workers and the subjectivities of young people living with CF, where some of the people, at any given time, are allowed more ‘airtime’ than others in the interplay of power.

Henriques, Hollway, Unwin, Venn, & Walkerdine’s 1984 publication gave psychologists a fresh set of tools to evaluate their work. One of these new
tools was the revision of theories of subjectivity. They inspired other psychologists to investigate disciplines that had implications for the new understanding of subjectivity (Gavey, 2002; Marecek, 2002), in which people are subjected to discursive power relations, personal history, meanings and perceptions, all encompassed in a web of social relationships. This allows for the possibility of viewing the psychological subject in new and exciting ways.

Walkerdine undertook research relevant to my study when she focused on ideas that she discussed in relation to Marx, who opted for the legitimation of science, so that scientific forms of knowledge and administration came to be privileged (Walkerdine, 1998). The goal of developmental psychology became the production of a social order that is rational, where democracy can function on the basis of producing useful citizens who will obey and conform to the moral and political order. Scientific forms of knowledge were adopted in hospitals and in the developmental clinics, whose function is to monitor and intervene in infant development according to a set of norms. In these clinics, infants who were born premature, or those who possess a genetic condition such as CF (termed deviants) were checked against so called ‘normal’ milestones of development. Scientific scrutiny of the child becomes measures of normal or abnormal pathological development, which has to be noted, classified and corrected (Walkerdine, 1998). In the child development unit in hospitals, the mere acts of crawling, standing and walking became closely scrutinised. Hence, child development issues became an object of governance in the follow up clinics. Within these clinics, which the CF infants needed to attend yearly, their physical and mental development was assessed. Deficits picked up during these clinic visits were acted upon with interventions of ‘enriching programmes’, aimed at producing the ‘norm’. The early experience of intervention through psychology to normalise CF sufferers as infants, can be seen to be acted out by young people in their own normalising behaviour. This early intervention forms what Walkerdine et al. (2001) have called a ‘rational bourgeois
subject', that is, one who places heightened value on self-expression, self-improvement and self transformation (Walkerdine, Lucey, & Melody, 2001, p.178). Walkerdine illustrated this point by stating that people can no longer be seen as being passively socialized into their appropriate gender roles.

Walkerdine did not agree that patriarchy is a monolithic force, which imposes socialization on girls. Instead, she says, it produces positions for subjects to enter (Walkerdine, 1989). Therefore, people 'position themselves' by participating within the available sets of social meaning and practices. Walkerdine expressed this point in the context of classrooms.

Female teachers and small girls are not unitary subjects uniquely positioned, but produced as a nexus of subjectivities, in relations of power which are constantly shifting, rendering them at one moment powerful and at another powerless… (Walkerdine, 1989, p 4)

I am also aware that the young people living with CF are produced as 'a nexus of subjectivities' in the discourse of CF, in relations of power with their doctors, which are constantly shifting, rendering them at one moment powerful and at another powerless. This theme will be explored in my analysis chapters.

4.43 Judith Butler

Butler is described as the most influential American feminist philosopher of gender identity (Blumenfeld & Breen, 2001). Butler's work is relevant to my research because she provides political accounts of subjectivity and insists that a theory of the construction of subjectivity is integrally linked to a theory of power. Butler insists that in order to understand the operations of power it is necessary to understand the subjective performance of power. She states:
We are used to thinking of power as what presses on the subject from outside...But if, following Foucault, we understand Power as forming the subject, as well as providing the very condition of its existence and the trajectory of its desire, then power is not simply what we oppose but also, in a strong sense, what we depend on for our existence and what we harbor and preserve in the beings that we are… (Butler, 1997b, p.2).

The formation of the subject is not possible outside of power because power forms us through simultaneous processes of submission and mastery. It is this very relation of power on/with the subject that Butler called ‘subjectification’. Power works on creating the subject in two ways: one is power as a condition of possibility for the subject, and the other is power as taken up by the subject’s own actions. Both these forms of power sustain as well as subordinate the subject (Allen, 2006). An example of the paradoxical conditions whereby subjectivity is made possible is seen when the young people who attend the CF clinic attend, because they accept the subjection of the CF discourse, only to subvert the smooth running of the clinics by ‘disappearing’ to do other (social) things when it is their turn to see the specialist. This contradiction will be explored in chapter six of my analysis.

Butler argues that a theory of power is so integral to a theory of subjectivity that it is impossible to theorize the subject without theorizing power. Butler argues that power forms and is performed by the subject. She says, “for power to act there must be a subject” (Butler, 1997b, p. 203).

Butler therefore explores the relationship between the operation of power and the formation of subjectivity. She breaks this process down to two fundamental relationships, the process of becoming subordinated by power and the process of becoming a subject (Butler, 1997b). Butler developed this argument by maintaining that subjection occurs via both the regulatory and
productive effects of power. She elaborates that power functions by imposing itself on us so we come to internalize and accept its terms. We become fundamentally dependent on these terms for our existence. This subjection is the ‘dependency on a discourse we never chose’ but which ‘paradoxically initiates and sustains our agency’ (Butler, 1997b, p.2). Therefore as part of the conditions of becoming a subject, we undergo subordination and mandatory submission. This is because as an individual we cannot become a subject without first becoming subjected, or undergoing ‘subjectivation’, so the agency of the subject becomes an effect of its subordination (Butler, 1997b). Therefore, central to the creation of the subject is the condition of possibility for the subject to eclipse power with power. This eclipse of power with power becomes the site for the subject’s agency (Allen, 2006). This is what Stern refers to as

Agency and subjectivity – the doer of the deed – are neither eliminated nor denied …The process of reiteration by which subjects are continuously constituted opens a space in which the constituting forces are opened to being reworked. (Stern, 2006, p.113)

I need to understand how my participants are able to accept genetic power as the condition of living as a person with CF, and yet make that power into a ‘condition of possibility’ for a viable life that exceeds the terms of medical discourse. The narratives of my interviewees appeared to be infused with such possibilities.

Butler takes up and critiques both Foucault and Freud to theorize her vision of subjectivity. Butler maintains that Foucault fails to constitute the subject by not adequately addressing the psychic formation of subjectivity (Butler, 1997, Campbell, 2001). Therefore, she calls on Freud’s psychoanalytic theory to understand the formation of the subject. Butler believes that one is unable to account for subjection without a psychoanalytic account of the formative or
generative effects of restrictions and prohibitions. The subject is dependent on power for its existence but can wield power at the same time. However, rather than accepting the dominant psychoanalytic view that there is one repressive and normative ‘Law’, Butler believes that a network of regulatory norms and discourses produces the subject and generates desire (Butler, 1997a).

Desire is a Lacanian term to express lack (Lacan, 1977) as condition of the living. This desire is ‘falling in love’ with the ‘self’. Only the very terminally ill person lacks desire, ‘falling out of love’ with the ‘self’ as illness attempts to diminish the self (Frank, 1995). Frank discussed the concept of desire as a need for ‘more’, in a consideration of the ‘production of desire’ in chronically sick persons. The sign that an interruption on the disease has occurred is what the medical fraternity called a ‘remission’, a temporary wellness, in which the person becomes motivated, and the beginnings of ‘desire’ are felt, and wanting something like new shoes, or dental work signals the ‘falling back in love with the self’ (Frank, 1995). These forms of behavior signifying longing are also seen in hospitalized young people living with CF, for instance in seeking ‘time out’ during treatment to go shopping. This discussion will be followed up in chapter seven.

Butler takes up the problem of desire when she asks how subjects come to desire their own subjection (1997b). This can be seen at work, in the context of my research, in the ambivalent pleasures, as well as pains, of being the subject of medical discourse, and also in my research participants’ longing to be ‘normal’.

4.44 Bronwyn Davies

Davies has been instrumental in making available Butler’s theory for research in education (Davies, 2006). It has also been useful for me to link both Butler’s and Davies’s work into ‘healthy moments’ in the lives of the
young people living with CF, to explain the narratives of their lived experience of surviving CF. Davies has taken up Butler’s theory of subjectification in an analysis of specific practice situations, thereby clarifying Butler’s point that at the heart of becoming a subject there is the paradox of a simultaneous occurrence of mastery and submission in the formation of the subject.

Although Davies’s work focuses mainly on the fields of education, she articulates poststructuralist theory in a way that is useful to my understanding of young people living with CF and their lived experience. Her interest in ‘subjectivity’ is followed up in research that centers on seeking to understand how children are both ‘made subjects’ and how they are ‘agents’. People are seen not as passively shaped by active others, including ‘social structures’: rather, they actively ‘take up as their own the discourse through which they are shaped’ (Davies & Banks, 1992, p.3).

Davies contends that discourses and discursive practices, which constitute subjects, also position them within particular situations. I utilise this theory of positioning to show how my participants position themselves within particular discourses in positive or marginalised ways in relation to chronic illness and genetic diseases. Davies also states that, while certain attributes delimit the capacity to access certain social positions - an example within my research could be CF patients wanting to become first class athletes - these positions are not fixed or immutable. It is in this unstructuredness that a space can be opened up for poststructural subjects to produce themselves, at least momentarily, as something apart from the discourses in which they are constituted (Davies, 1999). Davies explained that this fundamental idea leads to an understanding of the person as process. Hence, the person is not unitary but multiply constructed. Within this process are subjectivities coming, not from an essential core of the person but from the discursive practices, which the person is reconstituting, and through which the person is being constituted. This idea has helped me to understand the multiple and contradictory positions played out by my participants in their narratives about
how they handle compliance to medication. This will be discussed in chapter six.

Within the theme of ‘subjectification’, Davies holds the same view as Butler and Foucault, in that subjectivity within poststructuralism is understood as double. The subject is simultaneously constituted through discourse and yet at the same time becomes a ‘speaking subject’ pushing at the boundaries of our own subjection by transgressing it to open up new insights (Davies, 1999). Davies talks about the dual nature of subjectification: of being simultaneously subjected and becoming an agentic or ‘speaking subject’, a term which embraces the meanings of ‘agency’ and ‘performance’. Davies quotes Foucault as not being concerned with the issues of individual subjects, but with subjectification per se, in that he is interested in how human beings are made subjects over time and how our subjectivity is discursively produced. Similarly, Stern, who takes up this view, says:

“We must, then, interrogate how we are made into subjects, and what the consequences, both welcome and unwelcome, of such making are” (Stern, 2006, p.113).

The phenomenon whereby we are made subject appears to depend on a co-visibility of power relations, thus creating a possibility for people to resist the dominating tendencies of power. One such example is vividly illustrated in the young people living with CF and their attitude to medication. These young people are subjected to the powers of medication. They need medications to stay alive and healthy. The stories from their narratives illustrate not only that they accept the subjection to medication but also take on the role of ensuring that they ‘do’ medications for themselves because they want to be as healthy as the norm.
4.5 Creating CF subjectivity: A poststructural perspective

The subjectivity of young people living with CF is shaped by discursive practices that operate in different ways and contexts. In other words, the poststructural subject is never fixed and final but is always in the process of becoming, and is subjected to forces that may not be open to conscious inspection and rational analysis (Davies, 1999; St Pierre, 2000). This is because subjects are believed to be located in multiple discourses simultaneously being taken up in various subject positions amongst the forces that regulate subjectivity, which sustain some discursive practices and silence others. Therefore, when a subject exhibits agency it constructs itself by taking up discourses available within cultural practice and, at the same time, is 'subjected, forced into subjectivation by those same discourses and practices' (St. Pierre, 2000, p. 502). What St Pierre means is that the construction of the poststructural subject involves this 'double move' of being simultaneously subjected, and, at the same time, taking up agency through particular discourses, power relations and social positionings. The multiple narratives of the young people living with CF contain numerous episodes that involve this 'double move' of constituting and being constituted.

4.51 Subjectivities of young people living with CF

In the beginning of my research, when I was working as a genetic counsellor and clinic co-ordinator with the CF team, I was under the impression that the young people I cared for were living in terrible disease conditions and under the discursive power of CF. My concept of their plight in life was gleaned from the many emergency admissions I saw during the period that I worked as a paediatric emergency nurse ‘putting band-aids’ on self harm and overdose behaviours. Our limited role in the emergency department was to admit, stabilise and refer young people to the psychologist on duty. We did not get involved in their continuing care. From these few encounters with young people living with CF, I had a sense that there may be many sad and problem saturated stories to be unravelled. My objective, influenced by
narrative therapy but also by the normative discourse of development, was to explore multiple narratives for some alternative or situated ‘truth’, which I thought I may be able to use to propose a kind of bridge which these young people may be able to use to cross over into ‘liveable’ adulthood. This was a period in my life when I was predominantly embedded in a positivist model of care and worked in situations which underscored the discursive power of CF, making it appear totalising.

However, what I found from the multiple interviews I conducted was that these young people were telling me a different story of their multiple lives. Their stories were infused simultaneously with the struggles and the pain plus the joys of living the ‘conditions of possibility’ (Davies & Gannon, 2006, p.16) made available to them as young people living with CF.

In trying to make sense of the subjectivity of these young people, I have learnt from Foucault’s theory to view the CF team not only as authority figures, but as part of a web of power relations. They work through the discursive practices of the clinic, acting both to subjugate and empower their own subjectivity and that of the young people (Lupton, 1997). I have also learnt that subjects are complicit in discourses because they take up positions within them and have an investment in their continuity. This learning has enabled me to work reflexively with my own positioning and subjectivity, within and against the dominant medical discourse of CF.

4.6 Subjectivity in my research

To understand how subjects living with and surviving CF are formed, I want to theorize their subjectivity through analyzing their positioning, within and against the disease discourse through which CF is constituted and that is used to designate the social location of the young people living with CF. Within this context it is not the content of CF that interests me, but rather how
subjectivity operates through language systems available to these young people in the discursive categories of everyday talk as embedded in social action, purpose, and meaning. Poststructuralist theory is a radical discourse that I will utilize because it allows me to straddle the sickness / wellness dualistic discourse and move beyond taken-for-granted meanings. I wanted to find a way to generate a non-dualistic mode of thinking about the health of these young people who are labeled as living with CF, so that they can be read as (un)well, instead of alternating between being positioned as either well or unwell.

### 4.7 Data analysis of subjectivity in the next three chapters

The next three chapters will cover my data analysis of the subjectivities of the young people living with CF within the three themes of normalization, resistance and performativity. These three themes are chosen to celebrate the multiple ways these young people challenges the hegemony of the medical discourse. For these young people, the medical is a ‘bipolar’ discourse that is necessary to their existence because it sustains as well as governs them. In my odyssey of listening to their narratives and walking in their shoes, the recurring theme that resonates from their narratives is one of ‘living the conditions of possibility’ (Davis & Gannon 2006). These conditions of possibility can be better understood through the three concepts that loosely organize my data chapters: ‘passing as normal’, ‘resistance’ and ‘performativity’. My object is not to produce right or wrong arguments, for as Potter (2000) says “...the object is not to produce watertight lines of demarcation but to indicate areas of overlap and tension between the different forms of construction” (Potter, 2000, p. 99).
4.8 Conclusion

This chapter explored the notion of subjectivity and some of the theorists who develop a poststructuralist theory of subjectivity relevant to my research. Their theorizing of subjectivity will contribute to enriching my data analysis and understanding the narratives of my participants. Embedded within my data are the inevitable ‘power-relations’ proposed by Foucault that weave like the non-coding genetic material (junk DNA) through the narratives of the young people’s livable lives. I compare ‘junk DNA’ with Foucault’s ‘power relations’ because Foucault pointed out that power belongs to no one, but functions in relationship between institutions, groups, bureaucracies, the state, and these relations of power are not set in stone. Power relations can flow from one point to another; they are mobile and contingent. Similarly junk DNA or non-coding DNA belongs to no one but functions in relationship with the genome of a cell; such DNA are mobile and move around and have a significant influence on gene activity which is not definitive but contingent (Biemont & Vieira, 2006), just like Foucault’s power relations. As I mentioned in the earlier part of this chapter, Foucault states that the subject only comes into existence through the interplay of power and language where one group of people tries to constitute another through power and knowledge. My data is similarly embedded within these power relations, and my aim is to try to understand how this affects the narratives of my participants. Butler too states that ‘power exerted on a subject … constitutes the instrument of that subject’s becoming’ (Butler, 1997b, p.11). That is why I say that power relations function like the non-coding genetic materials, whose presence is contingent but necessary.
CHAPTER 5
DATA ANALYSIS

5.0 Introduction

In the last chapter, I introduced the concept of subjectivity. The following three chapters will explore the subjectivities of the young people living with CF through an analysis of the interview data.

The intension of this chapter analysis is to read the narratives of these young people through a lens of ‘normalisation’, in order to understand how they construct themselves as ‘passing as normal’. The sense I take from their narrative tells me that this group of young people does not experience ‘normality’ as a taken-for-granted state. Since birth they have had to regulate themselves with medication to stay ‘normal’. As I mentioned in an earlier chapter, living with CF does not mean they are ‘sick’ all of the time. They all go through degrees of wellness, and from their stories I interpret that they treasure this feeling of wellness, and are constantly trying to sustain it. This is one important way that these young people take up a position of agency in order to carve out ‘liveable lives’.

This analysis will be divided into two sections. Section one will be devoted to exploring the meaning and concept of ‘normalisation’ and related theorists. Section two will look at how young people negotiate their subjectivities in relation to their multiple ways of ‘passing’ as ‘normal’.
SECTION ONE

5.1 Normalization

Normalization is derived from the word ‘norm’, which according to Foucault, came from the period of history during which population control had to be exercised to mobilize a large number of people (Foucault, 1979). McNay described Foucault’s view on normalization as “… the routinized modes of behavior that are so deeply inscribed on the body by disciplinary modes of power that they seem natural or normal…” (McNay, 1994, p.112).

Foucault and Ewald describe normalization as an operation of bureaucratic and disciplinary powers (Ewald, 1991). The ‘population’ becomes a site of wealth and manpower that has to be governed. This is called regulatory power, and operates on gender as well as social and cultural norms. The framework of regulatory power is constituted in relation to the need by the state to ‘police’ births, deaths, marriages, and the demography of the population as a means of social regulation for the practice of equity and constraints, and as a categorising and regulatory mechanism (Ewald, 1991). However, normalization also involves self-regulation through a process of actively taking up subjection. Individuals choose to take up particular discourses as constitutive of a normality they come to desire. These are practices of ideological and discursive positioning whereby individuals locate themselves in meanings and regimes of truth, and in desires that motivate them (Walkerdine, 1991). These actions and desires to be appropriate, recognizable and valued subjects become for these subjects an active form of subjection. The process of subjection includes actions taken up in the process of accomplishing oneself as ‘normal’ (Davies & Gannon, 2006), which for my participants, means living as if they do not have CF. In this understanding of normalization, normalising power works together with what Foucault called ‘an autonomous aesthetics of the self’ (Foucault, 1985) to produce subjectivity.
The notion of normalization as ‘an autonomous aesthetics of the self’ is taken up by Bordo (1993), who expanded on Foucault’s version of the politics of the body. Bordo contends that Foucault contributed two views of the politics of the body, one being social ‘normalisation’ and the other, social ‘resistance’ (Bordo, 1993, p. 183). This chapter will expand on the former view, the social normalisation discourse. Bordo argues that for Foucault,

“Modern power is non-authoritarian, non-conspiratorial and indeed non-orchestrated; yet it none the less produces and normalises bodies to serve prevailing relations of dominance and subordination” (Bordo 1993 p. 191).

Within this argument, the normalization process is intricately involved with the notion of power, which in this instance is not deemed to belong to any individual or groups but is understood as a diffused network of forces in our society. These forces are neither random nor haphazard, but intimately tied to the discourses and to our dominant cultural practices in the dimensions of space, time, desire and embodiment. Our subjectivities and selfhood are maintained through taking up individual self-surveillance and self-correction to norms. An example is the ‘self-creating’ normalization taken up by women in their uptake of cosmetic surgery, within a consumer discourse that offers plastic surgery as a form of self-determination and choice. This notion of power is ‘productive’ yet also insidious because of different power relations that exist, for instance, within the popular media and the general population. Popular media has the power to construct the representation of ‘a defect’ in physical appearance with its utilisation of high fashion images of long-legged, slender-hipped models as normalising standards. The media’s normalising standards are used to promote the image of personal choice and self-determination, rendering the coerciveness of the discourse invisible. This coerciveness is tied up in the rhetoric of the body you are born with and your decision of what to do with it and is, in a nutshell, a form of social normalization. Applying this rhetoric of choice and self determination to
young people living with CF means that when one is born with CF, it is one’s
decision to stay healthy or take the consequences. In this instance, the
‘consequences’ are discursively bounded by the medical powers of CF.

Butler (2004) also discusses normalization as ‘created’ through medical
intervention, particularly in relation to the construction of ‘norms’. Her
definition of a norm is:

A norm is not the same as a rule, and it is not the same as a law. A norm operates within social practices as the implicit standard of normalization. Although a norm may be analytically separable from the practices in which it is embedded, it may also prove to be recalcitrant to any effort to decontextualize its operation. Norms may or may not be explicit, and when they operate as the normalizing principle in social practice, they usually remain implicit, difficult to read, discernible most clearly and dramatically in the effects that they produce (Butler, 2004, p.49).

Butler suggests that the process of normalization can be taken up in a variety of ways. Giving the example of the medical intervention of surgical procedures used as regulatory powers on babies with ‘aberrant’ sexual characteristics to create the ‘norms’ of culture, she states:

The question of surgical “correction” for intersexed children is one case in point. There the argument is made that children born with irregular primary sexual characteristics are to be “corrected” in order to fit in, to feel more comfortable, and achieve normality. Corrective surgery is sometimes performed with parental support and in the name of normalization, and the physical and psychic cost of the surgery have proven to be enormous for the persons who have been submitted, as it were to the knife of the norm (Butler, 2004, p. 53).
Another example of normalization practiced on religious grounds is male and female circumcision of babies, which could be thought of as literally submitting to the knife of the norm. Given the babies’ age and size, anaesthetics are not used in the performance of these surgical procedures due to the negative side effects of depressed respiration. In addition, these babies suffer untold discomfort from having urine soaked nappies making contact with the surgical wound. This remains an unspoken distress because babies are unable to verbalise their pain, which is silenced and elided to fulfil their parent’s and/or community’s conformation to the ‘norm’. Female circumcision usually involves removal of labia and clitoris, so the consequences are much more than the initial pain. Social requirements are reasons given in communities where young women are not able to marry unless circumcised.

Another notion of normalization within the context of negotiated social practice is found in the discourse of health and illness: the ‘medicalised norm’. Butler suggested that the naturalized effect of being ‘healthy’, ‘female’ or ‘male’ is the sign of a practice of normalization. Normalization is performatively constituted, and the ‘normal’ subject is ‘hailed’ into being, much like Althusser’s example of the man on the street assuming citizenship by taking up the subject position of one who is guilty when hailed by the policeman (Althusser, 1971). Within the context of CF as a genetic disease, individuals who have the disease become categorised outside the norm of the ‘healthy’ in medical discourses. However, it was found within this research that young people living with CF were able, in part, to refuse having their body inscribed within the cultural notions of CF as a disease.
5.2 Normalization as a process of stigma

I wanted to explore the shifting and complex subject positions my participants take up and juggle in relation to being ‘stigmatised’ as having the disease CF (Goffman, 1963). Goffman defined ‘passing’ as ‘the concealment of creditable facts’ (Goffman, 1963, p. 42), and saw ‘passing’ as being associated to the degree of its ‘visibility’, and it’s ‘known-about-ness’. Whether a person can pass as normal is interrelated to how physically visible the stigmata is. Within this context, young people living with CF do not possess any visible deformed physical features except for clubbing of the fingers due to sub-optimal starvation of oxygen metabolically (see photo below).

**Figure 8 Clubbed fingers**

Therefore, they are able to pass as ‘normal’, unlike individuals living with Downs syndrome, who can readily be recognised by the physical manifestation of their condition.

Goffman’s work illustrates the expectations of a society which demands that individuals exercise some control over their ‘deviancy’, by *passing* as normal, thus keeping from public view the overt manifestations of their illness such as
embarrassing dysfunction of bowel or bladder, which are emblems of what Frank identified as a ‘spoilt identity’ (Frank, 1995, p. 32). Frank conceptualised the notion of ‘spoilt identity’ in his exploration of the ways people are able to ‘proclaim’ their bodies and decide whether to ‘associate’ or ‘dissociate’ themselves from the signs of their illness within the practice of normalization. Frank extended Goffman’s concept of stigma into the fields of health and illness, saying that with most ill persons the practice of ‘passing as normal’ lies with maintaining a strict control over their symptoms with medication. He explains ‘passing’ in terms of the fact that we live in a world of ‘restitution narratives’ (Frank, 1995, p. 75). What he means by a restitution narrative is the expectation of contemporary culture that ‘health’ is the ‘norm’, where the ill person’s sick role is expected to be a temporary phase. The restoration of health is the normative expectation. This notion of ‘health’ does not take into consideration chronic illness like CF. I have found the narratives of my participants to contain multitudes of ‘restitution stories.’

Whitehead, Mason, Carlisle and Watkins (2001), identified the stigmatization process as having psychological and social consequences for individuals as well as marginalized groups. They identified the workings of stigmatization as part of cultural practices within a discourse of social exclusion. Whitehead et. al. recognized that within healthcare settings being ‘deviant’ or not ‘normal’ is often legitimised inside the illness context. However, outside of the illness context, these same ‘deviations’ can lead to ridicule, fear or disgust. One such example is that if a person smells of incontinence in a hospital setting it will be tolerated, but within a shopping complex, this would not be acceptable, since it is outside the bounds of the ‘norm’. The discourse of social exclusion creates and maintains the expectation that individuals will exhibit social competence and conform to the ‘norm’.

Social competence is thus fundamentally to do with appearing as normal or unremarkable within the terms of available, apparently transparent categories. An ability to appear in this way requires the performance of a set
of normative capacities and signs. Sometimes the features that disrupt this appearance are outside of the control of the person (Davies 1990).

One of the many themes and common narratives that emerged from the stories of my participants was the story of creating normality in their abnormal world. This narrative reveals how both ‘submission’ and ‘mastery’ are involved in the formation of these young people as subjects. Their submission is to accept that their CF is abnormal, but in their mastery of ‘liveable lives’, they also subvert the discourse of CF. In the context of this research this submission to and mastery over the discourse of CF is what I call the process of ‘normalization’.

This section of the data analysis proposes to examine the process of normalization of the subjectivity of young people living with CF through the work of Foucault, who sees the subject as constituted through relations of power. Subjectivity, in this view, is made by the relationships of power, subordination and resistance that prevail everywhere. Foucault says:

“…the individual is an effect of power, and at the same time, or precisely...it is that effect, it is the element of its articulation. The individual which power has constituted is at the same time its vehicle” (Foucault, 1980, p.98).

What Foucault means by this statement is that we are the very material of power and it finds its expression through us. Therefore, we as ‘subjects’ came into existence through power, language and knowledge. The power invested in us is not only dispensed by monarchy and from the state, but a technique of power that we invest in ourselves in our bid towards normalization in order to fit into society’s ‘norms’. Rose called this form of governance an act of self-scrutiny in the world of social control (Rose, 1989).
SECTION TWO

5.3 Data analysis

The following data analysis will be divided into themes as follows:

- The discourse of refusing to be inscribed as having CF.
- The discourse of ‘passing as normal’.
- The discourse of ‘medication’ as a realization of normalization.
- The discourse of being ‘normal or healthy’ in a ‘sick’ environment.

As I have already mentioned above, normalization is a prevailing theme the young people in my research take up, and are vulnerable to, because of their need to be incessantly self-creating in order to overcome a CF ‘defect’ they are born with.

5.4 The discourse of refusing to be inscribed as living with CF, and the ability, in part, to refuse to be inscribed

Davies describes this notion of refusing to be inscribed in terms of re-inscription:

…Her desires may well be the results of bodily inscription through metaphors and storylines that catch her up in one way of being/of desiring from which she has no escape. But now she can discover new storylines, invert, invent, break the bounds of old structures and old discourses… (Davies, 1999, p.67).

Fiona’s story

This process of bodily inscription and re-inscription as discussed by Davies was illustrated by a 17 year young person living with CF, when she was asked how and when she realised she had CF. In telling her story, Fiona
describes how at first she took CF to be normal. She imagined everyone had CF and that CF was the norm.

Fiona:
Yea, well I always thought, it wasn’t as though I had CF, it was just that everyone had CF. I wasn’t anything different. So I was either normal and everybody was normal, or I had CF and everyone had CF sort of thing. CF was the norm, so I went to school thinking that everybody had physio, everybody had millions of tablets a day, you know, it was just part of everybody’s life sort of thing, until I think the first day at school or something like that, I swapped lunch with somebody and in my lunch was the pancrease enzymes so it was a bit of a fiasco at school...

Until she went to school, she had not understood herself as ‘other’, nor experienced her condition as ‘abject’, since this ‘abject’ other is constituted through the recognition of difference, of something not quite normal (Butler, 1993, p. 15). This positioning of herself as the same as everyone else led to a “bit of a fiasco”, a memorable event in her life because up until this moment she had understood her categorisation of CF as normal since she thought everyone has CF. This was a pivotal point in her life:

I’ve always thought that was a pivotal point because I realize that, okay, not all kids have CF sort of thing...

At this pivotal moment, Fiona takes up the discursive categorising of herself as having CF and as being not like others. The taking up of this positioning is what Butler referred to as the “paradox of how the very possibility of subject formation depends upon a passionate pursuit of a recognition which ... [can be] inseparable from condemnation” (Butler, 1997 a, p.113)
Fiona is condemned to surviving CF and to living inside this categorisation. Rather than being normal, she is categorised through a medical condition and becomes constituted in terms of illness. What is interesting is that Fiona did not fully take up this categorisation as the defining feature of herself. She both accepts CF as part of her story and rejects it:

... but yeah it has always been a part of me but it is not what defines me sort of thing as a person...

Fiona (re)positioned herself as in part outside the category of CF, by relegating it to one ‘part’, but not the whole, of herself. She is a person who has CF, not a CF victim who struggles to be a person. She does not always have to make her CF condition visible. In primary school, she was able to pass as normal because ‘not many people knew’. It was basically ‘oh yes, she had asthma or something’, because she did not take many days off school and she was pretty healthy.

The teachers knew in case something went wrong, but my friends didn’t really need to know. And at primary school you know, you play hopscotch sort of thing, you don’t really get into deep and ‘meaningfuls’ and things like that...

The way she tells it is that at primary school no one got into anything ‘deep and meaningful’ ‘because you just play hop scotch and that sort of thing’. You are not obliged to confess the ‘truth’ of your existence as constituted within the CF discourse. Fiona was able to assume normality and not have to get into any self-disclosure about living with CF because only the teachers knew or needed to know. The relationship she had with her primary school friends was articulated through normative capacities for childhood play as ‘let’s go play some tag or something like that’.
Neil’s story

Neil was also able to (in part) assume normality at primary school because his medication was kept at the school office, where he would collect it and take it before his lunch break. His friends did not know about his CF until he was 12 years old. During his primary school years, he maintained that primary school friendship did not have the depth of 12 year olds, because they did not go into each other’s houses. But at high school, the practice of going into and out of each other’s houses means his friends got to know that he had CF on account of him being seen to be taking medication.

Neil:

* I don’t think I had CF… I ask… think […] at primary school I just pick it up at the office took it, then went on my way to lunch.
* My friends might not have known till about twelve or so… When we hang out around each other’s houses and that […] and see that I have to take tablets and everything…

It is remarkable that Neil himself did not accept the categorisation of having CF at first. Later, as he got older, through familiarisation with his medication and different friendship practices, there was a (dis)closure of himself, to himself and to his friends. All his primary school friends did not do home visits so he was able to assume normality. But in his teen years their friendship group adopted the practice of 'hanging around each other’s houses', and that was when his friends knew that he had CF.

I asked Neil if his life would be any different if he did not have CF. I wanted to know how he managed to live inside the categorisation of CF, and if he imagined life differently beyond that categorisation. He replied:

* Yea yea, I would have, whhhoo (such a big sigh), a big change though… It would be much different… do a lot more stuff…
Neil knew that his life would be different without CF because he had four other brothers who did not have CF. His big sigh expressed the (un)spoken subjection to and production of CF. Nevertheless Neil lived in a very active environment - when I visited to interview him at home, there were boys running in and out of the house in the time I was talking to him and the interview was shortened because his brothers were waiting for him to finish so they could ‘go do things’. The active lifestyle meant his brothers included him in everything they did. (They were waiting for him to go sailing with them). He was socialised into normality and categorised as normal by his brothers, which he himself took up as well when he said that CF did not bother him.

Yea, I don’t think I really like care much of it now ... Well it doesn’t bother me any...

Neil was socialised into normality so he took on the norm of the family, and became a member of the ‘healthy active’ dominant group. If he got sick he turned to his medication to get well, and so slipped back into being ‘healthy’ and taking on the family’s dominant discourse.

Yea just you know, if I get sick, I just stay on my meds and that... Well stick to my Pulmozyme...and when ever I like get real unwell, I keep going on my Pulmozyme and take all my Ventolin that will help me out

For Neil, it was important to belong to the ‘norm’. When I asked him how he imagined life without CF, he imagined himself doing a lot more things – yet he had already taken up a position of doing within a family discourse of vigorous physical activity. This slippage of belonging to the dominant group of his brothers’ clan may be contingent most of the time but he overcome this ‘slippage’ by treating his ‘bouts’ of illness as a mere inconvenience to be
‘gotten’ over with. In this ‘restitution narrative’, getting ill is just an interlude in one’s normal life (Frank, 1995).

5.5 The discourse of ‘passing as normal’ or normalisation as a condition of passing

The difference between being inscribed as living with CF and passing as normal is found in the participants’ different styles of living the conditions of possibility within the discourse of CF. Most of my participants’ subjectivities swing between being constituted as living with CF and passing as ‘normal’. In this section of my analysis, I illustrate the discourse of ‘passing as normal’.

Fiona and Neil’s stories both illustrate that ‘normalisation’ is a process taken up by young people living with CF in order to pass as normal. In doing so they have to work on their bodies to achieve normality. In Fiona’s situation, she regularly uses her Pep mask to help clear her clogged up lungs so that she is able to breathe.

*Fiona:*

*It was basically oh yeah she’s got asthma or something along those lines…*

For Fiona, having clear lungs and being able to breathe allows her to pass as normal. She permits her occasional wheezing to be defined as ‘a normal bit of asthma’, which is a common complaint amongst the general population and does not involve a process of stigmatisation.

Neil, who had a milder form of CF, was seldom hospitalised except once in year two of his primary school, which he recalled in the following manner:
Oh yea when I was in year two, I went to clinic for a check up, I was really sick, that day, and I went to hospital

Usually, though, Neil was able to achieve ‘normality’ with less effort than participants who were more severely affected. He passed as normal most of the time. Neil uses Pulmozyme, an inhaled form of enzyme that cleaves the long strands of mucous in the lungs and renders them liquid to be coughed up or drained via the back of the throat into the digestive system.

Neil’s strategy of passing as normal was expressed by Goffman as the ‘concealment of creditable facts’, where categorised persons who know that they are different from others can choose not to reveal it to others. Although Goffman is working from a different theoretical paradigm to Foucault, Butler and other poststructuralists, I find his concept of ‘passing’ a useful way to understand young peoples’ active self - constituting within the discourse of normality. According to Goffman, this form of categorising persons is established by society where social settings allow for classifying a person’s social identity (Goffman, 1963, p.42). This means that one may be categorised as having CF but can pass as normal. What is fascinating in this study is how life for young people living with CF can be different when they can pass as normal. This is the next theme I want to explore. What I found remarkable were the multiple and creative ways these young people managed to story their ‘precarious lives’. Some of these examples show how they positioned themselves outside the discourse of CF in passing-as-normal.

Butler states,

...subjection is neither simply the domination of a subject nor its production, but designates a certain kind of restriction in production, a restriction without which the production of the subject cannot take
place, a restriction through which that production takes place.
(Butler, 1997 b, p.84)

What Butler means by ‘subjection’ is similar to what Goffman classified as the attributes of ‘virtual social identity’, the act of categorising or putting persons into ‘norms’. Butler’s talk of production is similar to Goffman’s version of a social identity whereby the process of active normalization is taken up.

Eve’s story

This process of normalization appeared to be taken up by the young people living with CF in their own creative narratives. In this next example, Eve positions herself within the discourse of sports when she talks about being ‘sporty’.

Eve:
I am very sporty, I do a lot of sport. Like I don’t know it doesn’t affect my play at all because it sort of you know gets rid of all the gunk in my chest and all that, so, like I feel like I’m a normal person though so, it doesn’t really affect me

Eve says that she “does a lot of sport”- she classifies herself as an athlete because she is a member of the representative team for netball in NSW. In the process of doing the sport, she gets rid of the mucous in her lungs. The sport changes her body, making her able to breath like a normal person. Her reasoning is worth commenting on so I illustrated her four points as follows:

1. CF doesn’t affect me because I’m sporty.
2. Because I’m sporty I get rid of the signs of CF (the mucous).
3. Because I don’t have mucous on my lungs I feel normal.
4. Therefore CF doesn’t affect me.
So while CF is central to her argument in that one has to be active, sporty, in order to manage the mucous (the CF), the activity of sport leads to her feeling normal, and to being able to claim that she is normal and CF is irrelevant.

Her need for passing as ‘normal’ is reiterated when she goes on to describe herself in terms of the influence of her family and her genetic inheritance. She thus qualifies the reading I have done of what she says (see above), by saying she is not only sporty, but she is naturally sporty and manages to get rid of the mucous in her lungs as well. When she can breathe, she is normal.

... like we are a sporty family, so even if I didn't have it I guess that I still would have been sporty, but if I weren't...[...] I guess that my genes are like sporty...

The influence of the medical discourse about her CF is still evident in that she is forced into accepting that she has a genetic condition, and this can be seen as her subjection to the medical discourse. But in her narrative she manages to also subvert her genetic condition and appropriate the discourse of genetic medicine, by saying that her genes are sporty, so she has sporty genes blighted with the CF gene.

This form of discourse is described by Laws & Davies in terms of the ‘conditions of possibility’ in the discourse that she takes herself up in, where her subjectivity is not only what is desirable, but what is recognisable (and thus desired) as the acceptable ‘norm’ (Laws & Davies, 2000).
Christine’s story

In this next narrative, Christine is replying to my question about her lung function and her chest report during her last clinic visit.

Christine:
… they did that test and I had to run on a tread mill and they put like things on me?… (heart and saturation monitors) and they umm, they said like in the end they said I was healthier than a normal child about my age...

What is remarkable about this is the possibility of claiming that even if one has CF, one can be ‘healthier than a normal child’. Normality is thus shifted and divided – there are ways of signifying normality other than by not having CF. In fact Christine puts herself above, yet in an acceptable relation to, the norm by being healthier than the norm. Here Christine positions herself as an object of clinical science which Foucault called “a describable, analysable object” that can be classified and treated accordingly in the clinic (Foucault, 1977, p. 190). She is active in the uptake of the medical discourse where she had been classified by the pulmonary technician as having lung functions that are better than a normal child of her age. (Within the medical discourse, the yardstick of measurement for classification is taken from normal, healthy individuals, and it is from these measurements that deviant or abnormal classifications are derived. Conversely, to become classified as normal in the first place, one also has to be compared to the regulating discourse of abnormality.) For Christine, to be better than normal means that she can pass as a normal person.
Fiona’s story

I mentioned earlier that individuals living with CF do not have obvious visible physical features that may stigmatise them. It has been found within the narratives of my participants that many of them do not disclose their genetic condition to anyone they do not know well. This is because they are able to ‘pass-as-normal’ unless closely scrutinised. In this narrative Fiona says:

Yeah because I don’t want it to define me as a person, definitely, and I only tell people once I’ve known them so that way they can’t make a judgment of me because of CF. They’ve already known me as a friend, I’ve already become friends with them and then I tell them I have CF. So you know, that won’t influence their judgment at all.

The process of ‘passing-as-normal’ is a powerful discourse in our community because of expectations of conforming to the ‘norm’. Inscribing oneself according to the norm averts being hailed as ‘abnormal’ by others. Here Fiona is heard to say that she did not tell people that she is living with a genetic disease because she did not want them to make a judgement of her before they knew her. She talks about disclosing her genetic condition only when she had become friends with them because she did not want her condition to influence their judgement of her. This is a powerful discourse because Fiona is able to establish an identity, inside relations with a friend, that is normal, and then CF can be added to that normal identity without losing the initial sense of normality. Being ‘normal’ is the dominant discourse, and being different is not.

Kim’s story

In this narrative, Kim talks about disclosure in a similar way to Fiona. When asked if all her peers know that she is living with CF she replied.
Kim:

… maybe once somebody knows me but you know, and I am more open about it then.

Society’s normalisation discourses influence these statements about non-disclosure of the genetic condition. Frank calls it a “need to restore some measure of control” (Frank, 1995, p. 41). Since young people cannot control the CF discourse, they are attempting to subvert the power of CF to constitute their subjectivity and relationships with others.

5.6 The discourse of ‘medication’ as a realization of normalisation

In the discourse of being categorised through a medicalised condition, many of my participants both accepted ‘the process of medication’ to maintain normality and rejected being categorised as ‘sick’ in order to fit into society’s norm. Here are their stories.

Anna’s story

Anna was born in a country hospital, where she was not diagnosed as living with CF until she was twelve years old. Her early illness was treated as chronic respiratory infection. When she continued to lose weight in what the doctors called ‘failure to thrive’, she was sent to a metropolitan hospital for further investigations. There a blood sample was taken and sequenced and diagnosed as carrying the gene delta F508, for CF. After her diagnoses she was appropriately treated with pancreatic enzymes called creons. The following is an extract from her interview with me.

Monique: so Anna how has it been for you?

Anna: um, its all right I’ suppose, better, not being short and skinny

Monique: (laughs) is that what you think CF does for you?
Anna: (laughs) yeah, cause I used to be really, really, really scrawny’ n really, really, really short... [...] I’m on creons been growing and gaining weight

In this narrative, Anna has taken up the authority of doctors in following their instructions about treatment to resume normality (Frank, 1999). This form of medical regulation is described by Walkerdine as a “mimicry of scientific process” because “development could be watched, monitored and set along the right path” (Walkerdine, 1999, p.21.). Since Anna commenced on her pancreatic enzymes she had been monitored for weight and height gain. She expressed being happy with attaining correct weight and height. In explaining Anna’s discursive positioning, one needs to realize that, when positioned as she is, Anna is straddling what Butler would describe as the ambivalence of subjectification, as the effect of a prior power and as the condition of possibility for a viable life (Butler, 1997 a). In this process of subjection, the regulatory taking of pancreatic enzymes with fatty food, in itself, provides Anna with the possibility of moving towards normality. In taking regular enzymes she provides her body with compensation for a ‘lack’ that was her genetic predisposition. This action is normalising for Anna because it allows her to live a life where she is recognised and recognises herself as ‘normal’: as she articulated, “better, not being short and skinny”.

Dean’s story

During an interview with Dean I asked him about his last hospitalisation, expecting to hear a negative experience. What Dean said reiterated that many young people living with CF accept that the process of medicalization is essential. Dean describes hospitalisation as a positive. At home, it is bad to be sick, whereas in hospital one can set up a normal life.
Dean: No I sort of like hospitals but um, I don’t know why. I have no idea, but -

Monique: Is it because you link it up with safety?

Dean: No, no nothing like that, because actually when I go to hospital I want a room all by myself. I don’t know why I just like going to hospital. It is just crazy thing about me, I don’t know. I just like being there.

Monique: Because people don’t hassle you do they, when you go to hospital. The nurses and doctors don’t hassle you?

Dean: No okay, no, it’s just like I like having my own room in hospital and putting all my stuff all around it and watching TV.

Monique: You know you’ve got to be back for a tune up, is that what it is? When you go for tune ups.

Dean: No, I never do … it is only like if I am bad at home, really sick so anyway … I just … have to do … my antibiotics.

Monique: Antibiotics! and you go in for what, a week?

Dean: A week or two yeah… and yeah, so anyway that’s probably it.

The bad things are probably being sick, I don’t know, like breathing nebulising antibiotics it is like a real pain so just really crap.

In this instance, Dean says he did not like the experience of being sick, and he likes the experience of hospital better than the experience of being sick which he described as a ‘pain’ and ‘just really crap’. For Dean the process of normalisation means that in hospital he can be normal like having his own room and watching TV, be looked after, be medicated and have his things around him. Whereas at home, the medical regime can be just too hard.

Ruth’s story

In my next conversation with Ruth, I asked her about her attitude towards medication and CF and how she manages her life around it.
Ruth: And also I’ve said this before but something which helps me and it probably sounds stupid and I told one of my close friends this without CF and she thought it was really, really stupid but CF is just something that I have to do, like a chore because some of my friends have piano and their parents made them and they don’t have a choice for piano. Some of my friends have tennis lessons and I just pretend CF is like that, not pretend but -

Monique: Looked at it like that.

Ruth: Look at it like that you know, maybe just something like that because I tell my friend who does piano lessons and she goes I can’t believe you would compare CF, a genetic disease, with having piano lessons. And I said well piano takes an hour out of your day everyday or two hours out of your day every day for practice. CF takes two hours of my day everyday, you hate piano, I hate physio, but you have to do it for your parents, I have to do it for me.

Monique: Which is more motivating.

Ruth: Exactly, it is. And everybody has to, everybody, like I look at school and so many people have things in their life that you don’t realise at first but they have to do it and for me I just think okay, piano lesson, okay physio time, I have to do it everyday.

In this narrative, Ruth takes up the position of normalising CF and compares it with the chore of piano lessons, which her friend has to do. Whereas Ruth’s friend “can’t believe” that Ruth would compare CF to piano lessons, the analogy holds from the viewpoint of poststructural analysis. Both piano lessons and the regime of CF constitute and regulate subjects and their capacities. She makes visible that having to spend an hour or two doing physio is comparable to her friend having to do an hour or two of piano
lessons. But she goes on to reiterate her agency by saying that she does physio for herself, whereas her friend does piano lessons for her parents. They both loathe the process of physio and piano lessons but at least Ruth does it for personal reasons.

As an interviewer with a background as a counsellor, I sometimes get caught up in reiterating comments made by my participants, and in this instance I turned Ruth’s’ reflexive gaze back on her talk by commenting on her move as more motivating. She agreed and situated the discourse of ‘everyone has to do things they loathe’ as part of normal life, and for her doing physio is like a part of normal life.

5.7 The discourse of being ‘normal or healthy’ in a ‘sick’ environment

This section examines how the young people are able to accept the category of being categorised as living with CF, and manage at the same time to subvert CF to live a normal life and attend to normal activities.

Kim’s story

In this narrative, Kim was trying to explain to me about the routines of her dance class, but somehow the discourse of CF manages to take up some of her talk.

Kim:

when I got sick and um, um had to have …um…cannulas every three or four days for two weeks... so the port got better it would be better to have a port right?... because it is better like... not to, to ...go in ... every time and have long lines…and that it is easier, I ... just... I have to be like careful... yea like if you hit it... it hurts but I don’t like... I don’t mind it like when I do my dancing like ... when I roll on the floor I don’t mind even with my gastrostomy...
Monique: … (surprised)… when did you get the gastrostomy put in…?

Kim: at the [...] beginning of this year… um … because I was underweight… I was eating enough but…since then yeah… I put on… I was 28 ish kilos, and [...] now I am 39 ish and grown a couple of centimeters [...] and I dance Monday and um Thursdays and Tracey (her friend) is coming to my dance concert [...] put on by um my dance [...] school and she’s coming and then she is staying the night. [...] at the mini concert do you know what I mean [...] I shake my little toot on the catwalk…

Kim is able to get into the “subjunctive mode” (Bruner, 1986, p. 26), speculating about a future performance of friendship and the accomplishment of a normative, sexualised performance of gender, in which her friend witnesses the concert in where Kim “shake[s] [her] little toot on the catwalk”. Kim littered her talk with the medical discourse, like colours in a prism: as one frame of talk flicks into the other Kim ‘embraces the medical discourse and articulates it’ (Hall, 1997, p. 77) so that her narrative becomes normalised and comprehensible. This instance illustrates what Foucault (Foucault, 1972, p. 39); refers to as a form of ‘discursive practice’, a practice of institutional sites, which position us in relations of power within institutions, like hospitals, schools and churches, and we are drawn into ‘relations’ with these institution and practices (Parker, 1999, p. 5). As illustrated from the above example, this discursive practice powerfully shapes the way Kim tells her story in a ‘matter-of-fact’ fashion.

Kim went on to sing to me a song she composed about her cat and wanted to keep on singing about her porta-cathe. Although she had to have two devices to keep her alive, a porta-cathe and a gastrostomy, her matter-of-fact acceptance of the medical discourse of living with CF provides her with agency.
Kim: Yep. Yep. Which one’s the microphone?
Monique: That’s the microphone.
Kim: I’ll sing you a song about my cat. [SINGS!]

Patricia’s story

The next episode I will analyse occurred in the Adolescent Ward where I was looking after Patricia, who had to be admitted for exacerbation of her lung infections and was hospitalised and needing nasal prongs oxygen. Although she was in hospital under treatment, she insisted on asking for shopping leave.

Patricia: I know that I am allowed day leave um… so can I, can I, go this afternoon? My um… cousin is coming in to um…take me shopping.

I read Patricia’s ‘need to go shopping’ as a normalising practice she brings into her life to subvert the discourse of CF. In the hospital environment her peers are admitted because they are sick, but Patricia wishes to stay in touch with normality by getting out of the hospital environment into the so-called normal world to do normal things like shopping.

Jude and Donna’s story

Next, I will consider an interaction between brother and sister as a complex interplay of processes of normalisation. Both Jude and Donna are siblings and both have survived and lived with CF. Donna is older than Jude by two years. During this episode, I was speaking with Jude, and my assumption was that having a sibling with CF would make having the condition more bearable due to shared experiences. However, Jude refused my invitation to the discourse I placed him in, and went on to talk about the ‘normal’
relationship of siblings fighting with each other because ‘that is the way it is in the real world’. This is his interpretation of normality. Jude was able to dictate his own set of relevancies when he says that most times when they fight he lets Donna win because he did not want to hurt her because of the ‘porta-cathe’.

Thus a brotherly discourse of ‘looking out for his sister’, who wears the external signifier of suffering from CF, is invoked to differentiate Jude from Donna. Jude also said that when Donna did not have a ‘porta-cathe’ they used to fight ‘all the time’ and there was no concession of allowing her to win the fight.

_Monique_: Yeah. … having a sister helps or not…

_Jude_: I don’t know. Cause me and Donna … thing we always rumble, but we fight, but I don’t really like to hurt her because she’s got a port… … So I just let her jump on top of me. So I don’t hurt her or anything.

_Monique_: Let her win.

_Jude_: Yea, But when she didn’t have it we used to rumble all the time.

_Monique_: Did you?

_Jude_: Yeah.

I read this as Jude taking on the currency of normality in his attempt to disrupt the discourse of CF to illustrate his relationship with his sister as just normal sibling squabbles, until the point when CF was made visible, at which point, Jude took up a position within another normative discourse, that of brotherly protection.

_Shelley’s story_

I was talking with Shelley about the implements used to assist in doing chest physiotherapy. I made the assumption that since Shelley loved to dance she would prefer to dance rather than do physiotherapy. Shelley subverts my
view of medical discourse as oppressive and talks about owning a PEP mask. In her narrative, she subverts my agenda to talk about the use of the device, by sidestepping the position I offered and embarking on a series of playful and funny distractions. The process of normalisation and wanting to be seen to be ‘healthy’ is a powerful discourse, especially in individuals already stigmatised as having a genetic condition.

Monique: Do you prefer to do dancing rather than - do you have a flutter or do you have a pep mask for your physio…
Shelly: Oh I have a PEP mask.
Monique: Oh you don’t need to use a flutter?
Shelley: I call it paint mask because it’s funny. It is really a PEP mask.

My agenda was to understand if Shelley was compliant with the use of the PEP mask. To ascertain this, I persisted with asking a leading question. I asked her if she used the mask in the morning or at night. Shelly still refused to take up the position I offered. Rather than answering my question, she subverted it by calling her PEP mask, ‘a pet’, so that I had to enter her playful narrative in order to clarify her meaning. Perhaps Shelley’s affectionate and playful naming of this instrument of medical technology might also relate to Judith Butler’s point that we come to desire our own subjection (Butler, 1997b).

Monique: Yes, so you use it in the morning and at night
Shelly: Sometimes I call it PET.
Monique: Your pet? Is it like a kitten pet?
5.8 Conclusion

This chapter of analysis sets out to look at the complexity of the interviews I have undertaken, in order to frame the role of 'normalisation' in the subjectivities of my participants. It can be seen that the intersection between CF, CF treatment and wanting to ‘pass-as-normal’ is a powerful discourse influencing the young people living with a genetic condition. The focus of the analysis was on the binary of subjection, where my participants were subjected to the discourse of CF and the varied and creative ways they were able to become speaking subjects by subverting the power of CF and so gain normality in their lives.
CHAPTER 6
SUBJECTIVITY, CF AND ACTS OF ‘RESISTANCE’

These young people have learnt to survive within the web of power relations of the medical discourse. Their narratives tells me that they are subjugated by the discursive practices of the clinic but also work with and against these practices in order to take up agency as viable subjects (Lupton 1997). The concept of ‘resistance’ throws light on how these young people are not totally governed by the medical discourse of CF. Acts of resistance allow them some control over they way they manage their illness and expand the ‘conditions of possibility’ for living with CF.

6.1 Introducing resistance

Within psychodynamic psychology, ‘resistance’ is a defense against unthinkable or unbearable self-knowledge. This sense of resistance as negative and defensive has flowed into psychological practice, where ‘resistance’ and ‘non-compliance’ may be identified with each other as pathological responses to be interpreted and overcome (Kottler, 1992). In Marxist and post-Marxist theory, resistance is a movement that struggles against social forms of domination that have a power base, such as the state, capital and the military. However, according to Foucault’s analytic of power, resistance is a decentralized and localized response to the multiple operations of power, so that everywhere there is power there is resistance. A poststructural reading of ‘resistance’ makes visible and revisable the power of medical discourse and how CF is constituted. Practices through which young people living with CF are marginalized or stigmatised (Goffman, 1963) for having a genetic condition, and their everyday acts of resistance, can be read as a fight to be treated as ‘normal’. Acts of resistance have been interpreted by the medical discourse as acts of unreasonable non-compliance, but a poststructuralist reading can open up a way of making sense of that non-compliance. Bottrell links resistance to ‘identity work’.
“Resistances are defined as practices which express opposition to rules and norms in specific contexts, and which contain critiques of social relations, from the lived experience of marginalisation” (Bottrell, 2007, p. 599). Resistance ‘interrupts domination’ of the less powerful by the more powerful (Scheurich, 1997, p. 71). In relating this concept to my data, my participants are engaging in acts that interrupt the domination of the medical discourse of CF.

6.2 Resistance and power

Resistance is a concept that Foucault linked to relations of power; he said that power is neither inherently evil nor a negative repressive force. He stated that power is productive in that it can be found in the effects of liberty as well as in the effects of dominance, insofar as dominance produces resistance:

There are no relations of power without resistance; the latter are all the more real and effective because they are formed right at the point where relations of power are exercised; resistance to power does not have to come from elsewhere to be real, nor is it inexorably frustrated through being the compatriot of power. It exists all the more by being at the same place as power; hence, like power, resistance is multiple and can be integrated in global strategies (Foucault, 1980, p. 142).

Therefore, resistance, from my reading, represents ‘hope’ in power relations, where we can subvert power in order to undermine power, thus creating a space for agency. This agency lies in the young people’s ability to resist the binary of being healthy or sick. Young people living with CF work with and against the medical discourse in ways that give them agency in accomplishing themselves as ‘normal’.
Bordo defined resistance as “the creative agency of individuals” (Bordo, 1993, p.192). She goes on to state that power relations set up new openings for the potential of resistance. Resistance can take the form of making meanings to oppose or evade the dominant discourse.

Butler also states that “resistance appears as the effect of power, as a part of power, its self-subversion” (Butler, 1997b, p.93). In an important sense, power and resistance together are part of the same assemblage.

In his book “Discipline and Punish”, Foucault articulated a different kind of power associated with Jeremy Bentham’s architectural structure of the panopticon, which he called disciplinary power. Disciplinary power is dispensed invisibly within institutions such as prisons, schools and hospitals, where systematic practices of surveillance lead to self-surveillance, since, if you are never free from the suspicion of being watched, you begin to watch yourself. Disciplinary power has been taken up by the modern state such that power proliferates and is diffused into every aspect of human life (Foucault, 1977). St Pierre maintains that to offset the bleak totalizing potential of disciplinary power, poststructuralists developed the concept of resistance as an effect of a relation of power (St. Pierre, 2000). At the same time, disciplinary power is only one form of power, as Davies states that “Power is [also] the power to do things, to resist, to deconstruct, to write, to create...” (Davies, 1999, p.19).

6.3 Analysis
The analysis in this chapter will focus on narratives of young people living with CF and engaging in multiple acts of resistance. The analysis will be subdivided into four themes of resistance.

- Resistance as “at risk” behaviour
- Resistance as resilience
- Resistance as an act of non-compliance
- Resistance as a paradox
I acknowledge that some of these acts of ‘resistance’ could also be constituted as ‘passing’, as in the previous chapter. However, I am not interested in a fixed categorization of these young people’s narratives. Rather, I am interested in what the concept of resistance opens up to enquiry in the narratives of young people living with CF.

6.4 Resistance as “at risk” behaviour

In this chapter, I attempt to introduce a slippage into the concept of resistance, as it is generally used in psychological or medical discourses. In doing so, my analysis itself subverts the power of the category of CF, which labels such behavior within a risk discourse, as young people putting themselves ‘at risk’. In this section, I argue that my participants use acts of resistance to navigate a livable life (Butler, 2004), within the category of CF. In their quest for a livable life they engage in acts which are often read as ‘at risk’ events. The vignettes that I am interested in exploring do not cast a judgment on these acts of resistance but rather throw light on understanding a life circumscribed by CF.

I am a nurse and a genetic counselor caring for young people living with CF. When I started this research I was under the impression that CF was a terrible genetic condition that would necessarily fill the lives of these young people with sadness and grief. I saw them as having lost or restricted lives and participating in ‘at risk’ type behavior. But during the interviews with them I heard their narratives as speaking ‘a world view’ that lay outside my sphere of understanding the disease of CF. Their narratives were, for me, “opening new contexts, speaking in ways that have never yet been legitimated, and hence producing legitimation in new and future forms” (Butler, 1997a,p. 41).
Fiona’s story

When talking to Fiona, who is 17 years old and in her last year at high school, I asked her how she coped with CF.

Fiona: um, when I am just fed up with things I sort of, sometimes it is on the spur of the moment sometimes it is planned. Instead of just not doing physio one day, I do the whole day with no CF, no tablets, no nothing and it just gives me peace of mind, a little holiday away from CF because so it doesn’t become all of my life.

Within the medical discourse I would be required to describe Fiona as engaging in ‘at risk” behavior. From a poststructuralist perspective, however, I read Fiona as positioning herself as someone who is able to mobilize resistance in her own terms. She is trying to achieve a livable life out of problematic circumstances by both doing her CF regimes to stay alive, and also taking ‘time out’ from CF. This action seems contradictory, but it is not, because she does not allow the treatment to dominate her completely, at the same time as she achieves normality through treatment. I read her resistance as a way not to allow herself to be taken over by CF. She ‘arranges’ her plan of having ‘time out’ to be able to have a holiday from CF. Fiona says that she is not irresponsible about the requirements of CF. She talks about the power of the medical discourse as it is embodied in doctors and nurses frowning about her ‘at risk’ behavior. However, she reiterates her argument that she is taking ‘a little holiday away from CF’ by stating that she would not do it if she were sick. Rather than spontaneously taking wild risks. Fiona carefully negotiates the complexities of desiring normality, for she knows that neglecting her medications for too long would be risky and would make her sick. This is how she explains her actions:
Fiona: *Well, the doctors and nurses might disagree because I am just totally ignoring CF for a total day but yeah, for me I think it is, it is, not too detrimental to my health, which is the main thing. Like I wouldn’t do it if I am really sick you know...*

Fiona says she is just ignoring CF for a whole day, because she knows that it is not detrimental to her total health, and she qualifies this with the statement that she would not do it if she were sick. Her use of the term “really sick” signifies that there are gradations of ‘sickness’ that Fiona has identified. Fiona is sometimes ‘really sick’, which is perhaps when CF disrupts and takes over her life and when medications cannot be resisted even for a day. But there are also times when she feels really well, and at those times she can indulge in a CF free day (a day free of symptoms *and* free of medications). She is able to function through what Foucault called the regulatory and productive effects of power. The CF regime regulates her, but insofar as this regulation is visible she can take the regulation up as her own – thus becoming agentic in choosing to actively use the medication. Within her acts of resistance, there is also a sense of agency. Yet agency does not *only* live in resistance but also in taking up positions within dominant discourse.

Sometimes resistance can take on different forms. Foucault mentioned that resistance can be multiple and is formed right where relations of power are exercised (Foucault, 1980). I had not been aware during the interviews that my participants looked on me as one of the CF team governing their health status. Although I made it a point to interview all my participants in their home to reduce the power of the clinic, I was apparently unable to convince them that I was only interested in their story and not their compliance. Some of the data I gathered was scant and consisted of what a narrative therapist would call ‘thin stories’. I re-examined some of the ‘thin stories’ again in light of poststructural understandings and saw that they could be read as stories
of resistance, suggesting that they saw me in a power position engaging in surveillance of them (Foucault, 1980). The disciplinary power they saw me as having was initially invisible to me. One participant talked with me in monosyllable answers of ‘no’ and ‘I don’t know’ throughout the long interview. The following are some apparently ‘unpromising’ answers to questions I posed to some of my participants.

Harry’s story

Monique: When did you find out, you know... you knew you had cystic fibrosis... when did you become aware?
Harry: All the time.
Monique: All the time?
Harry: Yep
Monique: As soon as you can remember, you knew that you had cystic fibrosis, how, how did you know?
Harry: I don’t know.

Had I continued with my initial mode of analysis, this interview would have been placed in the recycling bin as unusable because the answers given did not make available to me the lived experience I had planned to uncover. However, reading these answers within a poststructural framework, I could read them as a form of resistance to CF, for example in the following lines:

Monique: Ok, so when you went to school, when you went to school, did you feel that you were any different from the other kids?
Harry: Not really
Monique: Not really?
Harry: Not till I came home.
Monique: Not till you come home? and then?
Harry: There is therapy.
Monique: Oh, oh, ok so you don’t have to, don’t have to take your pills at school?
Harry: No, I never have to do that either.
Monique: So you don’t have to take it to school to take it with your lunch, so you’re Pancreatic sufficient?
Harry: No.
Monique: No? ok, so you?
Harry: Never took it

When I take on a poststructural reading of this interview, this process makes available to me the attention to the hidden and less obvious. As Davies said, “poststructuralist discourse thus calls attention to the unmarked and the invisible in a number of ways” (Davies, 1994, p. 19). The interview can be read as resisting the CF discourse. Within the CF discourse, Harry practices ‘at risk’ behaviour. At school he does not take Pancrease, which has to be taken each time food is eaten; otherwise the food eaten will become non-nutritious because it cannot be absorbed by his digestive system. At home, he practices a different set of behaviours because he says that when he gets home there is ‘therapy’. He tells me he only takes his medication when he gets home. The reason he refuses to take medication at school became obvious to me via a chance remark made by his mother who told me that Harry’s friends at school do not know that he has CF. So his time at school gives him, each day, time out from CF, similar to Fiona’s day off.

When I asked him if CF made any difference to his life, he told me he does not want to know or even think about being involved with CF. He can be read to be using resistance in the form of not telling and thinking of himself in CF terms at least for the time he is at school, where he can ignore/refuse the idea of himself as one who lives with CF. However he is resigned to the treatment and takes up a position within CF discourse when he gets home. He does not totally ignore CF. This is not a ‘pathological’ refusal to accept CF, but a time of living free of CF (of both symptoms and treatment). This act
of resistance is to ensure his peers are not aware that he is living with CF. Zindani et al see ‘signs of denial or rebelliousness against their disease’ as an ‘at risk’ act (Zindani, Streetman, Pharm, Streetman, & Nasr, 2006). Reading it from a poststructuralist focus, I see it more as a form of agency, albeit one that is taken up within the inverse discourse of normality/passing, since from a poststructural perspective, agency is never outside of discourse. ‘Taking risks’ signifies the capacity to disrupt the totalisation of the CF discourse (Davies, 2003).

I knew that Harry was going on one of his many surfing holidays. I wanted to know, if Harry sidetracks his medication at school, would he ignore it on holidays, and how he would go about arranging his life around or against the discourse of CF.

Monique: Like, like for instance you’re talking about going surfing, on a surfing holiday?
Harry: Yep
Monique: So how do you, how do you work around it so that you can have your surfing holiday and be healthy for cystic fibrosis? have you thought about it? do you have? umm make special arrangements?
Harry: Pancrease, that’s about it
Monique: Umm hmm what about your Pulmozyme?
Harry: I am not going to take it.

Harry managed to subvert the CF discourse, practising alternating compliance and resistance, by taking some of his medications and overlooking others. Harry understood that living with CF meant that he could not ignore taking all of his medications over an extended period of time because he would get sick, so he did a selective culling of the essential medications when on holidays. The enzyme Pancrease is probably the easiest to take because it consists of capsules and looks like paracetamol.
Pancrease has to be taken with each meal depending on how much fat is in the food, the more fat the larger the number of capsules. As this is an essential medication to his health, he takes it. Pulmozyme is a living form of enzyme called Dornase Alfa, a mucolytic agent (cleaves mucous into small strands), and needs to be stored under ice and taken as a nebuliser. Harry would need to take with him mask, oxygen tubing and a pump, all adding to luggage and hence the visibility of CF when he was going on holidays. Next I wanted to know how involved Harry was about CF and whether he sought more information about CF.

Monique: So do you think it made any difference to you growing up because you have cystic fibrosis and your brother and sisters didn’t?
Harry: don’t think about it.
Monique: are you curious about cystic fibrosis? do you kinda want to find out a bit about it?
Harry: No.
Monique: you never had? you never asked?
Harry: No.

I realised that Harry just wanted to ‘live a normal life’ and his resistance is in part a strategy of escaping the subjection of CF by taking some but not all of the essential medication, and also taking in only the necessary minimum of information about CF. Like Fiona, this is his way of living free of CF for a time.

Monique: Ok and um, like for instance you know how during school holidays when you need to go in for tune up? do you fit your life around it? or do you just think oh well I’ve got to go in.
Harry: I just do it

At this point of the conversation Harry’s mother decided to tell me something new which explained for me some of the reason for Harry’s behaviour.
Harry’s mum: Harry has not told his friends that he has CF, the only ones who knows are the primary school friends not his present ones

Monique: Haven’t you? OK, Harry do you … why? hmm why?

Harry: No point.

Harry concluded with the words “no point” which as I understand was Harry’s way of summing up how he manages CF and is Harry’s resistance. As I had gained a wider knowledge of Harry’s life through my work in the CF unit, I was aware that at age 19 he already ran a part time successful real estate business in partnership with his sister. He spent his spare time surfing because it made him happier. He also found that the seawater and exertions from surfing made him feel fitter. This has lately been borne out via research that hypertonic saline in the airways has the ability to neutralize the viscous mucous in the airways (Havasi et al., 2008). Harry found a different set of strategies to the one prescribed through the medical discourse that enabled him not only to survive but apparently to thrive. The research by Havasi suggested Harry’s strategy made sense within some of the latest scientific research. I read Harry’s comments as simple truth statements, he told it as he saw it. I also read Harry’s actions as resistance to the CF discourse that enabled him to fit into the norms of his group of surfing friends. Since the disclosure by his mother that he had not told his surfing friends about his CF, I could understand his not wanting to take his Pulmozyme away with him because this medication is very visible. One cannot hide the sound of a pump delivering a steaming mask via a nebuliser, and this has to be performed daily for it to be effective to help lung function. Since Harry was surfing, he could get away with ignoring his Pulmozyme on his surfing holidays, and nevertheless continue to thrive. I read that Harry has built a resistance towards the production within CF discourse of an ‘abject’ body, which is the binary of the ‘norm’ of the healthy fit bodies of his surfing friends.
In refusing to analyze Harry’s refusal of some medications as non-compliant, I, as a researcher, am also practicing resistance to the CF discourse as it is generally taken up by clinicians. Bordo described this form of resistance as a ‘reading against the grain’ to illustrate the “unstable nature of subjectivity and the creative agency of individuals” (Bordo, 1993, p. 193). In this instance my reading of the data ‘against-the-grain’ underscores the creative agency of Harry the surfer/ Harry the young man living with CF / Harry the real estate agent.

Gwen’s story

Another narrative with ‘thin stories’ was elicited in my interview with Gwen. When I asked Gwen what having CF meant to her, she replied with the word ‘medicine’. Gwen saw herself as different from her peers because she had to take ‘medicine’. She did not mention why she had to take ‘medicine’ because, as she understood it, the only difference between herself and her peers was that she had to ‘do’ medicine.

*Gwen: Medicine.*

*M: You were taking medicine?*

*Gwen: Yeah.*

*M: So when you got to school you had to take medicine and then so um and so what did you think, did you think that everybody had it or did you?*

*Gwen: No, different*

*M: You were different.*

*Gwen: I think so, yea.*

*M: You thought you were different because you had to take medicine?*

*Gwen: Yeah.*
Gwen compares the difference between herself and her peers by saying that she had to take medicine whereas her peers did not have to take medicine. However, she still resists, in the next excerpt, naming herself as living with CF, although she constitutes herself as needing to do medicine. I read this narrative as Gwen being both constituted by CF, and resisting it, in that she rejected using the term. She substitutes CF with the taking of medicine, an action even ‘so-called-normal’ people have to do sometime in their lives, so the taking of medicine is ‘not a big deal’. This is underscored in Gwen’s next reply ‘I feel normal’. When I heard Gwen’s reply that she feels normal, I realized that I, and not she, am doing the discursive work of positioning her as being sick and ‘having to take medicine’. We are often unaware of the discursive work we do as genetic counsellors due to the ‘pathologic lenses’ we wear in our encounters with people we care for. An unexpected benefit of this research has been an increase in my reflexivity and ability to take up a clinical and academic position within and against the discourse of CF. Scheurich discussed the concept of the interviewer possessing her/his own agendas at interviews when he said: “Many times I have asked a question which the respondent has turned into a different question that she or he wants to answer” (Scheurich, 1997, p. 71)

Monique: So do you think it has changed you in any way, having cystic fibrosis, growing up with cystic fibrosis?
Gwen: No, I feel normal, I don’t…
Monique: Yeah, except that you have to take medicine.
Gwen: Yeah, except I’ve got to take medicine and that.
Monique: So do you feel that it’s a bit of a drag that you’ve got to take your medicine to school … does that make a difference?
Gwen: No.

It is fascinating how in this next narrative Gwen continued to subvert the discourse of CF by not having to worry or be responsible for taking her medication because, as she said, her friends made sure she took her
Pancrease after a meal. In her resistance to taking responsibility for CF, she positions her friends as being responsible for her. This could be read within the individualizing discourse of risk and responsibility as an ‘at risk’ version of behavior, because Gwen is not willing to be responsible for managing the discourse of CF. Alternatively, it could be read as a very healthy attitude, insofar as Gwen has not hidden her need for medication from her friends, who can form a supportive community that helps take care of her.

*Monique:* So you remember every time you have a meal.

*Gwen:* Yeah they make sure I take.

*Monique:* Your friends?

*Gwen:* Yeah.

This next piece of information cast a light on my reading of Gwen’s resistance. Gwen positioned herself as someone not living with CF when she stated ‘the best thing is I am not so sick,’ which implied that she did not have a severe form of CF. She then goes on to stress that she does not allow CF to run her life day in or day out. She implies that she is not losing sleep over it, and resists allowing CF to take over her life.

*Gwen:* The best thing is I am not so sick… I don’t go to sleep and go oh I’ve got it, and I don’t wake up and go, oh, I’ve got it, I just slack off…

*Monique:* Are there days when you just feel- oh, don’t really want to do this..?

*Gwen:* Yea, when I have to do Pulmozyme, I have to force my self… in the morning…

Gwen told me that the medical regime was hard for her to stick to and that she had to force herself to do it. She felt she is lucky she does not have such a severe form of CF. I read her as having an ambivalent relationship with CF.
and as sometimes abjecting herself in relation to the CF discourse. According to Butler, the domain of the abject renders the territory (of living with CF) as 'unlivable' and 'uninhabitable'. This is evident in Gwen’s description of having to force herself to “do Pulmozyme”. However, this sense of abjection does not dominate Gwen, who finds ways of making her life viable in relation to CF. Bordo described the feeling of ambivalence as having a many faceted set of meanings, such that the rhetoric of ambivalence contains both creative and resistant responses (Bordo, 1993). In this example, I read Gwen’s ambivalence towards the regime of medication as a refusal to be colonized by CF. In many of the interviews I conducted, I found that many of my participants share this common attitude of ambivalence towards medication/ not wanting to be colonized by CF.

**Ophelia’s story**

When I spoke with Ophelia I asked her if her friends knew that she had CF. I had come to understand during my interviews that quite a few of my participants were not disclosing their genetic conditions to their peers. As a genetic counselor I understand this as an ‘at risk’ behavior, but using my poststructuralist lens I read this as a form of resistance, a way to re-inscribe a sense of meaning into their lives away from the discourse of CF. I asked myself, what is it that these young people are not doing or saying when they deny the existence of CF in their lives? Michele Davies called this mode of living as 'living the philosophy of the present', which means that rather than accepting that one may die in the near future, resistance is used to live as the celebration of the present, and not entertain what the future may hold (M. L. Davies, 1997, p. 566). The following conversation with Ophelia suggests that she may be ‘celebrating living in the present’ by not engaging with me in talking about the effect of CF on her life. Then again, it may be that my questions did not hold any meaningful associations for her, or I could read this as her mode of resistance towards the influence of the discourse of CF and of me as interviewer. Sometimes the interviewee may see herself or
himself as less powerful and may take control of parts of the interviewing process by simply not going along with the interviewer (Scheurich, 1997). Ophelia may see me as part of the CF team keeping surveillance of her and therefore she is able to subvert my intention with resistance.

Monique: did you tell your friends? did they ask you………?
Ophelia: I’m not sure, they probably would have, I don’t remember, no, short memory!

I read what Ophelia said as resistance to talking to me about the disclosure of CF to her peers, by saying that she did not remember whether she told her friends or not, and she calls on the excuse of short memory, forgetfulness.

Monique: That’s all right, its just, hmm trying to look back to see what its like for you then, what’s it like for you?
Ophelia: I was all right
Monique: Did you feel different…?
Ophelia: Hmm noo not really.
Monique: No?
Ophelia: Nope.
Monique: Did it change the way.
Ophelia: No.
Monique: Did it?
Ophelia: Nope.
Monique: So, you think… you don’t know whether it changed your life or not growing up with CF?
Ophelia: No I don’t talk about it; it doesn’t come up in our conversations.

In my initial analysis, I read that when questioned, Ophelia used ‘forgetfulness’ to resist talking about CF. However, when I deconstructed the narrative, I realized that my own practice of asking the participants what they
think about having CF is inappropriate because they don’t know about not having CF: having CF is all that they know and experience. This concept has no meaning; hence, their resistance to giving me any answer. One aspect of poststructuralist inquiry is that it has been liberating to admit to myself that I too participate in discourses that constituted these young people as ‘other’ to the ‘norm’ of not living with CF.

6.5 Resistance as resilience

I take up this second theme of resistance as resilience in the sense that Deleuze put forward as to what bodies are capable of. “Bodies are not defined by their genus or species, by their organs and functions, but by what they can do, by the affects of which they are capable” (Deleuze & Parnet, 1987).

Young people living with CF are capable of resilience. Indeed resilience might best describe some of the ‘acts of resistance’ my participants take up in their bid to live a life not totally taken over by the CF discourse. A group of psychologists, Luthar, Cicchetti and Becker define resilience as: “A dynamic process encompassing positive adaptation within the context of significant adversity” (Luthar, Cicchetti, & Becker, 2000). Here, I extend on the concept of ‘resilience’ by locating it, like ‘agency’ within a poststructural understanding of discourse and subjectivity. Thus I plan to focus on Deleuze’s understanding of the capacities of bodies in order to explore some of the narratives of resilience / resistance that my participants take up within the discourse of living with CF.

Kim’s story

When I spoke with Kim about the hobby she pursued, my agenda was to gain an understanding of how she manages her life within the discourse of CF. Kim spoke about her enjoyment of doing creative writing.
Kim: Ah well I like creative writing,
Monique: You’ve written much lately?
Kim: Um umm
Monique: You write short stories?
Kim: Oh some are long.
Monique: How long are the long ones?
Kim: Well pretty long,
Monique: And about what sort of character?
Kim: ha, ha, ooh I don’t…
Monique: its OK I just want to know about it, is it about a girl or about family?
Kim: Umm well it’s mostly about a girl, mainly adventures, fantasy, and several characters…

In deconstructing the conversation with Kim, I read it as ‘creative’ positive adaptation, the resilience of living with CF. She is capable of writing, of imagining other lives, like the adventures of a girl without CF. I say this because I know Kim in the context of my work at the CF clinic. I know that she writes for a hobby and I have read some of her work. She writes fantasy stories, several short stories and currently a full-length novel about the adventures of a girl set in magical worlds. The girl heroine does not suffer from CF but has the ability to achieve amazing feats because she possesses magical powers. I read this action as a form of resistance and resilience in relation to living with CF, which represents for her the ‘unliveable’ and ‘uninhabitable’ zones of social life. She subverts and moves beyond the CF discourse by engaging in creative stories of an imagined self and imaginative acts.
**Lewis’s story**

This next extract was taken from an interview with Lewis, a thirteen year-old boy. From my experience with my participants, I found that several of them were teased about their genetic condition. They had been positioned by their peers as abject. Sacks examined the process of categorization and concluded that categories are used to define people, for instance, as mothers, white male or people living with a chronic condition (Sacks, 1974). Sacks pointed out that there are many categories available to describe any one person, and he is interested in the contexts within which a particular category is mobilised. I needed to know why Lewis was categorised by his genetic condition, and therefore abjected, and not by all his other possible categories. In this instance, it could be that his peers are judging Lewis as not normal. Being teased at school is problematic under any conditions. I am particularly interested in how Lewis talked about his experience of being teased.

*Lewis: No, I get teased [...] well these are silly kids I … I just walk away from it, and sometimes I get into a fight, sometimes I don’t, I usually go around and do my own thing...[...]...they hang out with their friends and I hang out with my friends.*

I read Lewis’s response to being teased as an act of resilience and resistance in sometimes not allowing himself to be affected by teasing. He was able to say that the ones who teased him could be categorised in their turn, as ‘silly’, in which case he could walk away from them rather than fight; although sometimes, he said, he did fight. Davies sees children and young people as being subjected to “category-maintenance work” carried out by those who wish to establish adherence to a particular social or moral order (Davies, 2003, p. 52). Davies then describes the process of acquiring of ‘correct behaviours’ so as not to be classified outside the ‘norm’. What is particularly significant in my poststructural reading of this episode is that
Lewis did not enter into the narrative of himself as inevitably a victim because of CF. In his act of resilience, he positioned himself as having the power to walk away from ‘silly’ people or to fight back if appropriate. Lewis did not allow himself to be taken over by the category maintenance work of those who abject him, constituting him as not normal, and as outside the social/moral order. Instead, he positioned himself inside another social order. He associated with his own friends rather than be a victim to the normalizing regime of ‘silly’ others.

Fiona’s story

In this next excerpt, Fiona explains how she did not want to attribute her subjectivity to the influence of CF, but that she cannot deny that it has made her become more independent at an earlier age. In my reading, Fiona’s resilience / resistance takes the form of growing up faster than her peers.

*Fiona: Umm [...] I like to think that it hasn't [...] because I don’t want to attribute who I’ve become to CF, but in reality I think it has for sure [...] like I have had to become more independent more quickly in life [...] growing up faster for sure [...] and you are a more of “a live for the moment” [...] type of person to a certain degree.*

Fiona goes on to add that she has also become a person who likes to do as much as she can to enjoy the present to the full, and not think too much of the future, as a “live for the moment type of person”. In other words, resilience/ resistance enables her to pack as much into her short life as possible, and be freed, at least for the moment, from the normalizing pressures to think of herself as missing out on life when she may become sicker. This links back to an earlier conversation I had with Fiona when she talks about taking ‘a little holiday away from CF’ (a
day free of symptoms and free of medications), an act of ‘celebration of the present’.

6.6 Resistance as an act of non-compliance

CF is an incurable genetic condition, and its associated treatment has been described as complicated and life long (Llorente, Gracia, & Martin, 2008). These authors described the CF community as complying with only half of their prescribed medication. Physiotherapy had been found to have the lowest rate of compliance. Medical studies on non-compliance have concentrated on absolute and partial compliance (Abbott, Dodd, Gee, & Webb, 2001; Dodd & Webb, 2000). The medical assessment of compliance utilised two methods, the self-reporting method and pill weighing or counting method (Fitzgerald, 2001). The two categories of naming non-compliance are unable to tell us why and how non-compliance occurred. Another study believed that family functioning, which they called relationship quality (RQ) has implications for non-adherence behaviour. The study used the Treatment Adherence Rating Scale (TARS) to measure treatment adherence (DeLambo, levers-Landis, Drotar, & Quittner, 2004). This study found a weak correlation between relationship quality, (RQ) and child reported treatment adherence (TARS). These results report on the rates of non-compliance generated by objective measures.

Sometimes resistance in the form of non-compliance becomes a choice made by my participants. However, I am not implying that ‘non-compliance’ is more common in this group of people than in others living with chronic illness. In fact, many of the studies on compliance showed that young people living with CF were more compliant than people with other diagnoses were with treatment, which they believed had more repercussions on their lives (Llorente, Gracia, & Martin, 2008; Zindani, Streetman, Pharm, Streetman, & Nasr, 2006).
In this chapter, while not denying that some forms of ‘non-compliance’ may endanger young people, I am interested in understanding non-compliance differently, as resistance to the power of the dominant discourse of CF.

Doug’s story

In this interview, I wanted to know how Doug, a 16 year-old schoolboy who lived with his mother, stayed healthy and well without engaging in practices of self care. I asked Doug about his regime of self-care, in order to understand his experience of compliance.

Monique: So do you sort of do special things to make sure you keep yourself healthy?
Doug: Not really, I hardly ever exercise which is really bad for me and like seriously I hardly ever do physiotherapy, I do like nothing. But um.
Monique: You keep well.
Doug: Yeah.

Doug told me that he did not take on board the practices of staying healthy, so within the medical discourse he is non-compliant (Fitzgerald, 2001).

Monique: What are the things you do to keep well without having to exercise?
Doug: Um.
Monique: That’s the intriguing bit.
Doug: I don’t know my mum does acupuncture.
Monique: Okay.
Doug: And that probably keeps me well. I don’t know.
Monique: Oh she gives you acupuncture?
Doug: No she is just doing it at uni and hmm, she’s just uses me hmm as a lab rat.
Monique: She uses you as a guinea pig.

In this short conversation Doug not only told me about his resistance to doing physio but his non-compliance too. I knew that Doug had good lung functions and was seldom admitted to hospitals for intensive antibiotics treatment. Doug wanted me to believe that he had managed to stay healthy without much effort. I wanted to know how Doug was able to evade the medical fact that without physiotherapy one cannot achieve good lung function. It is through physiotherapy that lungs that get clogged overnight can be freed of the thick mucous build up. I wanted to ask Doug what he participated in outside the medical norm to achieve clear lungs. What Doug told me was something outside my sphere of knowing: that he participated in acupuncture performed on him by his mother as a student of acupuncture at the University. He allowed himself to be ‘a lab rat’ for his mother to practice on. Whereas Doug is not willing to comply with the medical regime of CF, he is willing to comply with another (complementary) medical discourse, when he becomes a ‘lab-rat’ in order to ‘help his mother’ in her studies. This illustrates the contingency of poststructural analysis in that, as Sacks alleged, it is not the naming of the category alone that counts, but why that particular category is used at this precise time.

Doug: Exactly.
Monique: That’s really good.
Doug: That’s probably why I don’t…
Monique: So you don’t even have to use a PEP mask?
Doug: Well I do but I don’t, I have to use it, but I never do.
Monique: Do you tell the physio that you use it?
Doug: No I don’t, I tell her I don’t and she just laughs at me.
Monique: So acupuncture must be helping, and you don’t mind using acupuncture?
Doug: I thought I should give it a try and mum like, just do it anyway umm keeps you well umm do it for yourself so I don’t have to umm exercise and stuff.
Monique: Because you have good lung functions and everything.
Doug: Yeah I know.

In reading Doug’s answers I could have judged him through the lens of the medical discourse and deemed him as non-compliant. On reading his story through a poststructuralist lense, I can see how he positioned himself in considering other possibilities available to him to achieve good lung function. The point is that he has good lung function even though he is non-compliant. In this sense he seems to confound the medical discourse, which presumes that compliance is the only cause of good lung function. But Doug’s mother appears to have found another therapy that works. While the efficacy of acupuncture as an alternative to physiotherapy might, in another discursive context, need to be scientifically verified, here I am interested in how this alternative functions narratively to challenge the narrow view of Doug as non-compliant. The picture that Doug is ‘healthy’, happy and yet apparently ‘non-compliant’ disrupts the strong hold of the negative and judgemental concept of non-compliance.

Anna’s story

Sometimes reading a non-compliance story can stretch the intersection of meaning in language and communication in creative and unpredictable ways, as in this next interview with Anna, when I asked her how she coped with having to take so many medications daily.

Anna: Mum goes …on to me umm […] umm “you’ve got to do it or you can’t watch TV” [laughs].
Monique: She does, does she? [laughs]… What happens when you grow older and go to live in a flat, what are you going to do?
Anna: I’m going to have a room mate or someone who will say exactly the same thing… (laughs and laughs).

In this story Anna told me that she still needed to be reminded to take her medications by her mother. Anna is 16, still at school and lives in a country town. From within the CF discourse, I read her to be simultaneously compliant and non-compliant by allowing her mother to ‘make her’ take her medications. This is Anna’s ‘active reliance’, a game she plays with her mother because she knows she will give in. She does not yet want to take over the responsibility of having to deal with CF. I remember the interview as being light hearted and infused with a lot of laughter. I read this as Anna allowing me into her game: her ‘compliance’ is embedded in a relationship in which she can both engage in resistance and comply. From a poststructuralist perspective, this suggests that she does not have to be governed by a dominant medical discourse which is able to stalk her every move. She is skilful in getting her mother to take the responsibility for Anna’s medication and ‘plans’ to bestow the same responsibility on her yet unknown flatmate. I reflected on why this episode was so amusing to Anna, and was open to the interpretation that Anna was playing out the ‘dominance-and-resistance’ discourse between interviewer and interviewee (Scheurich, 1997, p.71). This concept takes on the notion that ‘interviewing’ is a dynamic process where the interviewee will negotiate and create meanings of their own as to what they want to tell and what they wish to silence. Anna, in this instance, may have been resisting my interviewing, which made an assumption of the virtue of self-responsibility, and subverting the binary of compliance/non-compliance that typifies medical discourse.
Beth’s story

Beth was a young person referred to me by her mother, who had been keen for me to include Beth in my studies. Beth’s mother told me that her daughter had never spoken about CF to either of her siblings (she has a brother and a sister, both of whom did not have CF), nor to her parents, or any of her friends. Beth apparently lived in a world of “silences” involving CF. Her parents wanted to know if I could make a difference, and ‘open her up’. But, as can be seen from her answers, I was not able to penetrate the resistance she had built around CF. I have since re-examined my questions and have come to realize that Beth admitted at the beginning of the interview that she wished she didn’t have to live with CF, and that she has thought about it. But she told me that she did not see ‘being informed’ or ‘talking about it’ to others as strategies that will help her. I would have liked to engage with her just to ‘walk in her shoes’ for a while, but my questions, as the interview progressed, promote resistance:

Monique: It’s just I wonder if sometimes you wish you didn’t have CF?
Beth: Yea probably,
Monique: When would that be at school, at home when did you start to think like that?
Beth: I don’t know
Monique: Did you every think about it?
Beth: Yea probably,
Monique: So when you thought about it, did you want to know a bit about it did you look up books and things?
Beth: No
Monique: No, did you talk to mum about it
Beth: No
Monique: Did you talk to dad about it?
Beth: No
Monique: Talk to your friends about it?
Beth: No
Monique: How did you find out about CF?
Beth: I don’t know
Monique: You did find out, or you didn’t want to find out?
Beth: I didn’t
Monique: Didn’t find out or you didn’t want to Hmmm?
Beth: Didn’t care
Monique: Hmmm?
Beth: I didn’t care about it
Monique: You didn’t care?
Beth: No

Beth’s parents were concerned that whilst Beth is living at home they were able in part to ensure that Beth is compliant with her medications, but that this would change. Beth is now 15 years old, and they were worried that she may leave home in the near future. They were apprehensive about the possibility of her ‘non-compliance factor’. I read Beth’s resistance to CF and the possibility of non-compliance as one part of the chaos narrative proposed by Cassell (Cassell, 2004). Cassell stated that people suffer when confronted with terminal illness that represents a threat to the ‘body-self’. By not taking on the discourse of CF, I read Beth as wishing to resist this threat. On the other hand, I was aware of a ‘silence’ in the family dynamics around the topic of CF. The family may have taken on the discourse of ‘normalization’ and CF had become ‘other’ to the norms of the family, hence CF was not getting any ‘airtime’ in their conversations at home. Her parents were unable to bring up the topic of CF, and it was the mother’s agenda to use my genetic counseling skills to help Beth talk about CF. I took another approach to engage Beth in what follows:

Monique: who is your best friend?
Beth: Nancy,
Monique: Right and does she have CF?
Beth: no
Monique: But she doesn’t know
Beth: no
Monique: How do you reckon you could tell her? then you’ll become really, really good friends, share things, would you like to tell her?
Beth: I don’t know
Monique: you haven’t thought about it?
Beth: no
Monique: So, for instance you were Nancy right?, and Nancy is Beth, pretend right?
Beth: Hmm
Monique: If you were Nancy, and are best friends with Beth, would you like Beth to tell you?
Beth: probably.
Monique: can you think about it?
Beth: no
Monique: Must be hard not wanting to talk about it?
Beth: no
Monique: Do you think if you tell her she’ll still be your friend?
Beth: yea.

When I read this section of the interview I saw one facet of a play of power relations between interviewer and interviewee (Scheurich, 1997). As an interviewer, I had Beth’s mother’s agenda at the forefront of my questions in taking on the discourse of a genetic counsellor. In the way I phrased the questions I engendered an unequal relation with Beth. I brought a third person, Beth’s best friend Nancy, into the conversation as a means to support my agenda of getting Beth to see the ‘true’ benefits of talking about / disclosing CF. Beth was willing in part, to engage with me in the conversation about her best friend Nancy, but her resistance was still palpable when she said she could not conceive of thinking about telling Nancy about CF, and that she did not want to talk about it. In this instance my alliance with the
dominant discourse promoted further resistance. In resisting her mother’s and my attempts to have Beth take up a position as someone openly living with CF, perhaps Beth was resisting the CF discourse and trying to carve out a space for her own existence in a normal world. Beth made it clear that it was not, in this instance, that her friend would abject Beth if she told about CF - in fact Nancy, would want Beth to tell. Rather from Beth’s perspective, telling would inscribe her as a CF sufferer, a position she refused.

Dean’s story

My next participant Dean was non-compliant only when he was well, when he believed that regular medications did not make a difference to his life. He told me that he chose to do medication only when he was sick. I read this action as productive of someone who was both constituted by the discourse of CF when he was sick and practiced resistance to the power of CF when he was well so that he did not get taken over by the power of CF.

Monique: But when you’re sick?
Dean: When I’m sick I do it and then I miss out,
Monique: Yea,
Dean: Aww I do my Neb everyday, and Pep mask, was probably twice a week really,
Monique: So hmmm do you, have you, got days when you just forget or didn’t want to take anything?
Dean: Yes, heaps of them,
Monique: Heaps of them?
Dean: And I don’t think it makes a lot of difference.

I suggested to Dean that he may have just wanted to forget about CF and pretended that it did not exist, whereby Dean protested that, that was not how it was at all when he said,
Dean: No, no, if I knew, if I know I need to do it then I will probably do it, I will do it.
Monique: But if you’re feeling healthy?
Dean: No, then I don’t really, think that much of it
Monique: OK no problems, its just THERE!
Dean: Yes, just it isn’t like I can do stuff about, but since I can’t do stuff about it, it just doesn’t really matter.

Dean suggested to me that CF so obviously controlled his life that since he could not do anything about having the condition, he would subvert it whenever he could. At times I am unable to accept this reasoning. I seem to expect these young people to ‘do their medications’ all of the time, because, from within medical discourse, I believe that CF is there and in need of treatment all the time. At other times, I realize that these young people are in-tune with their bodies and that I as an outsider do not have their insider knowledge. Dean has the evidence of his own experience that he can be healthy even if he doesn’t do the medications all of the time. It reads to me as though he uses intelligent compliance rather than mindless, obedient compliance. He subverts CF when he is feeling well, so that he can feel normal.

Irene’s story

Irene, on the other hand has a different set of relationships towards CF:

Irene: Yeah, I’ve got to take control of my own life. I can’t keep relying on other people. I rarely do but like you know, my mum is a worry wart, she goes... You do this, five seconds later, did you do that?, Get up and do it ! ! ! . Sometimes she might be out... and I go... Mum’s going to be home soon, I’ve got to do it. I hate doing it when she reminds me.
Irene did not want to construct herself as ‘resistant’ towards CF. I read that she took up a discourse of choice and wanted to take control of her own life and her relationship with CF on her own terms. She channeled her resistance and her acts of non-compliance towards her mother. She said she was only non-compliant because she disliked being told by her mother to do the medications and physiotherapy required by CF. She described, vividly, periods in her life when her mother was not home, and how she felt compelled to attend to the needs of CF by herself before her mother returned.

6.7 Resistance as a paradox

My thoughts in this section hinge on a conceptualization of subjectivity. There is a paradox that challenges the binary of resistance and submission – since both submission and resistance to discourse forms the subject, and the subject actively takes up the conditions of its possibility. Therefore resistance has many different facets. Rose maintained that certain positions that are offered to subjects are impossible to live with (Rose, 1986) and offered the paradox that resistance and contradiction are sometimes taken up as a survival strategy.

Mary’s story

In this next conversation with Mary, I read Mary’s resistance as a paradox, a tension between being compelled to submit to subjection by the conditions of CF, and the mode of becoming an agentic subject. I say this because of my understanding of the paradox of ‘subjectification’ in French, *assujettissement* - which Butler describes as containing both the becoming of the subject and the process of being subjected. Butler says that “subjection is both the subordination and becoming of the subject” (Butler, 1997b, p. 13). If we take on the theory of subjection, then all acts have an element of contradiction. The process of becoming a subject is inherently paradoxical, and I note the
importance of specificity about how this contradiction is enacted in each of my participant’s stories. In some of the conversation with my participants, I have found their stories of resistance reveal the paradox at the heart of subjectivity. This paradox lies in a tension between being subjected to CF, and paradoxically becoming more agentic through the necessity that CF may invoke in its subjects to take action in order to survive.

_Mary:_

_I just think that I would probably take less hmm, not take less care of myself. But, but have less of a conscience of everything that I am doing, like, hmm, hmm its kinda molded into my life [...] like I have more responsibility having had CF and [...] you know I have to deal with things more myself because I am the only one going through this, I've, I've had to be a bit more independent than maybe I wouldn't have been without CF._

Mary said that, if she did not have CF, she would probably be less responsible about her lifestyle. I read her narrative as a paradox of resistance, (Mahoney & Yngvesson, 1992), because she attributed her achievement of a normative subjectivity to the discourse of CF. Mary stated that if she had been born ‘normal’ she would not have become the mature and independent person she is. She said that having to live with CF made her more responsible, more aware and more caring. She went on to talk about being an activist for organ donor awareness week, which was something she would probably never be part of if she had not had CF.
Ruth’s story

When I spoke with Ruth, I wanted to understand how she managed ‘bad’ days with CF. During my conversation with her she mentioned that living with CF, she had good days and bad days. This question is specific to how Ruth managed ‘bad’ days and I found her answers to be a paradox of resistance.

Monique: When you’re down... is there something that happened that really helped you deal with CF?

Ruth: Umm not at the time, but a really close friend that doesn’t have CF, she just said “get over it, you know, you didn’t chose it but you can’t change it, so just get over it and deal with it”. And that didn’t really help at the time and I didn’t talk to her for a while [...] but now when I get fed up with CF now, I just ... that advice is always in my head, just get over it, you know.

Ruth explained to me that sometimes when she is down she talked to her friend about her problems with CF. She remembered one incident when she talked to her closest friend and was surprised by her friend’s unsympathetic comments to “get over it”. Ruth said that at the time she was so upset that she did not talk to her friend for a long time. But on later reflection, she realized that she was unable to do anything about CF, so she chose to get on with it. The paradox here is how the storyline at one point of her life was not useful, yet on another occasion, she was able to take it up as a survival strategy (Rose, 1986). This paradox of resistance signals the fluidity of subjectivity in poststructuralist readings. The point illustrated is that our subjectivity is not unitary but subjected to different storylines and different subject positions of ‘choice or active resistance’ (Davies, 1993).
This next vignette of resistance as a paradox throws light on the contradictory power of language to give agency as well as to be read as an insult / abjection\(^{12}\). I was talking to Patricia about the process of being teased at school because both she and her twin brother lived with CF. It was apparent to me that Patricia had been classified outside of the norm and was abjected by her peers.

Patricia: Yes, I think it was in year one there was this boy called Toby [...] yea pretty mean [...] he said something about some disease we had, and to keep away from us, [...] my brother and I were sitting next to each other at recess, Toby was just being a real jerk, so [...] he was one of those guys who thought he was really cool because he wore his jumper backwards [...] I was sitting there going, hey, hey, he is such an idiot [...] and it didn’t really bother me.

Patricia was able to resist the dominant discourse of being named as being ‘other’ by Toby, who singled out both Patricia and her twin brother as having ‘some disease’. By naming Toby as ‘pretty mean’ Patricia was able to resist the position offered by Toby, which could be impossible to live with. I read this as a memorial story of resistance as a paradox. I say this because Patricia was able to recall the incident that happened ten years ago in its minute detail. I read this as Patricia refusing the ‘interpellation’ Toby offered to be identified as not normal. She was able to name Toby as a ‘real jerk’ who wore his jumper back-to-front, thereby reversing the gaze. She could resist taking Toby seriously because she was able to position him as someone who is not ‘cool’ as well as an ‘idiot’. She indicated that in the real

\(^{12}\) ‘Abjection’ is a concept developed by Julia Kristeva and the book where she most famously wrote about abjection is called ‘Powers of horror’. 
world, no one takes notice of ‘idiots’ or ‘un-cool’ people, and therefore their views and powers are easily dismissible.

**Monique’s story**

This next narrative is a vignette of my own experience with resistance.

One October morning whilst I was working at the Adolescent Ward, I was told to prepare for a new admission of a young person living with CF. I equipped the room with oxygen tanks and all the implements for monitoring oxygen levels and admitted Clayton to the room. He was quite breathless and needing constant oxygen. He looked pale, frail and very thin. He was a 19-year-old young man. I was a bit shaken by his attire because he was dressed in white, a sort of flowing shirt, (maybe his night-shirt, I thought). The CF specialist was informed of his admission after I had taken the medical history and completed the baseline vital signs. Clayton did not look to be in any distress although he needed continuous oxygen. He talked to me in a calm voice and I could see from his pale washed out eyes beneath a tumble of light brown hair that he appeared to be at peace with himself. After the specialist’s visit, I expected him to order blood and intravenous cannulation together with some form of medication. But his instructions to me were to keep Clayton comfortable and pain free. I looked through Clayton’s medical notes and saw the term N.F.R. written in red (N.F.R. in medical terms means not for resuscitation) and it was counter signed by Clayton himself. *(I was unable to come to terms with this decision).*

I asked one of the permanent staff in the ward about Clayton, and she said that he had been readmitted many times in the last two months and that he had terminal lung disease. She also told me that Clayton had refused to be put onto the ‘heart-lung’ transplant list. Apparently, Clayton ‘took up

13 Cannulation is a procedure where a needle is inserted into a large vein in order to obtain temporary access to the venous circulatory system for delivery of intravenous medication.
Buddhism in the last year. He had decided six months ago that he did not want any intervention, only to be comfortable and as pain free as possible. He died 24 hours later, asleep in his bed. When I thought about Clayton’s resistance I saw a contradiction in his decision, in that his viability and agency as a subject was, for him, paradoxically linked to his death. I also saw a contradiction in my own positioning of him within the medical discourse, where I would paradoxically feel compelled to prolong his life through means that, for him, were diminishing, rather than promoting, of his viability as a subject.

I can only look to Butler to explain this sometimes painful paradox of resistance and submission to discourse, and to highlight those contradictions beyond the reach of my analysis. Butler talks about subject positions as necessarily incomplete, that no ‘interpellations’ are entirely successful. She goes on to say, ‘You call me this, but what I am eludes the semantic reach of any such linguistic effort to capture me’ (Butler, Laclau, & Zizek, 2000, p.12).

In this chapter, I undertook the process of analyzing my participants’ use of resistance as a means of subverting the discourse of CF. The narratives helped to shed light on my understanding that illness does not necessarily dampen the enjoyment for living. The stories tell me that my participants engaged in ensuring that their lives do not get taken over or totalized by the medical discourse of CF.
CHAPTER 7
DATA ANALYSIS OF SUBJECTIVITY AS PERFORMATIVITY

The young people in this study construct themselves through not one but multiple narratives. Their illness narrative is but one part of their life (Philips 2003). The narrative self they have chosen to take up when talking to me can be understood as a ‘performativ[e]’ mode. Within the jouissance of the performative, the young people tell stories of how they are able to relinquish the constraints of CF and soar into narratives of achievement. Their narratives talk about how particular actions are performed in enjoyment of sheer living. Death is reduced to only one narrative possibility, rather than being the inevitable end point of a dominant narrative. By taking up the concept of performativity, I am able to detect how these young people give voice to performances of living. The concept of performativity suggests that the young people’s narratives and speech acts, in these interviews, rather than being simply a citation or repetition of existing discourses, bring new possibilities for subjectivity into being.

7 Introduction
This final analysis chapter explores the stories and subjectivities of the young people who participated in my research through Butler’s theory of ‘performativ[e]’. The theory of performativity takes up the metaphor of performance in order to shed light on the practices whereby the individual comes to take up her / his positioning as a subject. For Butler, although the subject is constituted through power, each iteration or performance of subjectivity is more than a mere repetition, allowing for the appearance of difference. This process traces the active emergence of the self through discourse, allowing for the surfacing of positions of struggle and conflict as well as having the potential for personal and social change. Davies and Harre suggested that the constitutive force of discursive practice in language
gives rise to social positions that one can take up or refuse though that refusal may be difficult (Davies & Harre, 1990). They maintained that language itself has a constitutive power wherein the individual can mobilise language as well as be mobilised by it. Butler discusses the speech act as having the performative power to institute as well as to close off meanings (Butler, 1997a). This feature of language is illustrated in my participants’ talk and will be pursued in the analysis section of this chapter.

7.1 Lyotard’s influence

Language is not only used to describe the world, but to play with it, a process which Wittgenstein referred to as language games (Burbules, 2000). Lyotard developed Wittgenstein’s version of language games and used it to form his theory of how a dominant metanarrative can assert its ‘truth’ from the perspective of an authorised discourse like Christianity, or the government. The authorised discourse develops other ‘truths’ from those held in the margins such as ethnic minorities, women and children, who become excluded and powerless. Lyotard’s version of language games proposed the collapse of grand narratives in favour of local narratives that have their own sets of controlling discourses. This allows for a proliferation of minority discourses, rather than language being determined by grand narratives of dominant groups. The importance of language as a social resource means it can be incorporated to function not only as a means of communication but also as a social phenomenon. Lyotard named the possibilities of language as having a place apart, a space

…that has not become public, that has not become communicational, that has not become systemic, and that can never become any of these things… within this space is the language that hears marginal voices, the language of literature and art. (Lyotard, 1993, p.105)
Lyotard goes on to say,

Our role as thinkers is to deepen what language there is, to criticize the shallow notion of information, to reveal an irremediable opacity within language itself. Language is not an instrument of communication (Lyotard, 1993, p. 27).

Lyotard explicitly states that language is more than only a tool for verbal communication. Moreover, in a situation where more than one person is speaking, there is a tussle for meaning between several sets of utterances.

… Every utterance should be thought of as a move in a language game so to speak, to fight, in the sense of playing, and speech acts fall within the domain of a general agonistics. So, a move can be made for the sheer pleasure of its inventions. Great joy is had in the endless invention of turns of phrase, of words and meanings, the process behind the evolution of language on the level of parole (Lyotard, 1984, p.10).

From this perspective, it is through the play of language that speech acts become ‘performative’.

7.2 Butler's concept of performativity

Butler uses the performativity of speech acts to interpret the struggle for legitimacy of speaking subjects. She called this theory ‘discursive performativity’ (Failler, 2001, p. 50). She believed that through speech it is possible for us to achieve meaning (making) against regulatory norms, thus challenging the normative conditions of speakability (Butler, 1997a). Butler, in proposing the theory of discursive performativity, enabled the use of speech as a site of ‘agency’ and political resistance for the subject in
discourse (Failler, 2001). Through performativity, we can use language to function for us but we are also subjected to other people’s attempts to address us; consequently, we are constitutted as subjects in discourse. For Butler, performativity signals the potential to perform meanings other than the ones stated and to allow speech acts to resignify conventional meanings, to think outside the square (Butler, 1997a). Butler’s concept of performativity can be used to make sense of the accomplishment of my participants as ‘just a normal person’. The concept of performativity proposed by Butler is a useful means of analysis that I can use to interrogate different subject positions my participants take up, especially within discourses that sustain lines of power and power effects in their encounters with the discourse of CF.

7.3 Subjectivity as performativity

According to Butler, subjectivity is not the origin of action as it is in a humanistic view, but is the consequence of gendered routines of performativity. I take this to mean that for young people living with CF, the routines of CF treatment produce their subjectivity, but do not determine it entirely, since each time they take up these routines produces a possibility of subversion. The concept of ‘performativity’ in relation to the subject or subjectivity means that the performative practices taken up allow for actions that are both constitutive and constituted. Our subjectivity is fractured through sexual and racial identifications, as well as being regulated by social norms, and becomes for us the taking up of a certain particular subjected position (Barvosa-Carter, 2001; Butler, 1997a). Barvosa-Carter points out that the theory of performativity is by no means limited to gender:

It requires us to attend to the socially constituted self as multiply constructed – a self whose performativity applies not to one axis of gender norms, but to a variety of different culturally derived axes
each with its own sets of linguistic tools –(meanings, values, and practices) and identifications (Barvosa-Carter, 2001, p.128).

If we view language as a form of discursive social practice, then language allows for an imaginative exploration of the ways the young people living with CF transform their subjectivities in their precarious struggle with being signified as the subjects of CF, the theme of this study.

Jackson states that “[p]erformativity is Butler’s theory of gender that accentuates a process of repetition that produces gendered subjectivity” (Jackson, 2004, p. 679). She states that the act of repetition is not merely a “performance by a subject but a performativity that constitutes a subject and produces the space of conflicting subjectivities that contest the foundations and origins of stable identity categories” (Jackson, 2004, p 675). The stable identity categories or conventional normative order consist in discursive, sedimented and taken-for-granted ways of being which poststructuralist theory is interested in disrupting. This disruption allows for a reworking of the CF subject so that a space can be created for transformative and agentic work. The theory of performativity provides a powerful means to reconceptualise the CF subject, and also suggests that I need to be reflexive about my interviews with my participants and view the encounter between us as a performative construction of subjectivity within relations of power.

Jackson said that “poststructural theories of subjectivity capture the active process of taking up certain subject positions in an ongoing process of becoming – rather than merely being – in the world” (Jackson, 2004, p. 674). This notion of performativity is described by Dumont as a de-centring subjectivity, whereby subjectivity is continuously being reconstructed (Dumont Jr, 2008).

Translating all these notions into my research, I can see that the young people surviving CF, in part, ‘abject’ the fact that they are living with CF. This
means that not having CF is the normative order against which surviving CF becomes a ‘difference’. The domain of the ‘abject’ according to Butler is understood as an “unlivable and uninhabitable zones of social life” (Butler, 1993, p. 3). My participants can be seen to reiterate and to performatively exceed the prescriptions of medical discourse. The concept of performativity allows me to deconstruct how they celebrate being much more than just a person living with CF in the performance they bring into the living of their lives.

DATA ANALYSIS

My data analysis of performativity will consist of four sub-themes

- Performativity as discursive agency
- Performativity as response to the burden of normality
- Performativity as subversion of the medical discourse
- Performativity as iterability

7.4 Performativity as discursive agency

According to Davies, agency is discursively produced but an individual can take up the ‘choice’ of alternative discursive practices within her / his social world (Davies, 1990). Moreover, the modern individual is constituted as someone who ‘chooses’: who accepts responsibility for her / his own actions (Rose, 1996).

In the extracts that follow, my participants seem to take up the challenge of agency and perform a continual reiteration of their performative bodies to create ways of living which then count as a life worth living, the living of a viable life and its possibilities.
Todd’s story

I was talking to Todd about self-care practices in CF. Todd told me when he takes up long distance cycling he clears out his lungs, and can constitute himself as a cyclist with clear lungs. Others might want to dispute this and say that Todd is ‘really’ a person living with CF. But what Todd tells me is that he can accomplish both subjectivities, as living with CF and as an athlete with clear lungs. He takes his medications and in that act acknowledges the primacy of his diagnosis as having CF. But he also accomplishes himself as a cyclist. When I use performativity theory, I say that as Todd cycles along the road, clearing his lungs, he is the thing that he performs; he becomes the cyclist with clear lungs. A poststructuralist theory of language accepts that language is alive and can be mobilized to change Todd’s constitution within it. He can stretch his meaning of CF to include athletes who are very healthy and do not need to use the boring pep mask. His performance of cycling accomplishes, as a performative act, himself as a cyclist.

Monique: Because you’re aware, that with CF, you need to be healthy, are there, special things you do, yourself, anyway, as a self care thing, to make sure that you are on track with CF, and you know it’s a healthy thing?
Todd: Yep, um obviously I take all the drugs I’m supposed to take, and generally I don’t have a problem with that, Pep mask, when I’m sick, I tend to get lazy about It, it gets boring as hell, I hate it!! Monique: You could have music with it!!
Todd: No just distracts you!! but, anyway I cycle a lot? and I run, so…
Monique: Oh you cycle? in competition?
Todd: yes,
Monique: Good, and running?
Todd: Oh, not very long distance at the moment, ah…
Monique: So you like cycling? and you do that as a pastime?
Todd: Yep, like especially when you feel your lungs building up, within two days after your last ride your lungs can fill up really quickly, and you think oh, its time to go out again so I get out and it clears it right out, and its very clear for another day or two so.

In poststructuralist analysis we are not concerned with uncovering the hidden meanings of anything so we have the freedom to gaze at the regulating and constituting functions of language, looking at how discourse gets produced and regulated (Bove, 1990), especially in the sphere of performativity. In this section of the analysis, I want to think of my interview with Todd as ‘performative’ and to dismantle the layers of sedimented discourse which flow back and forth between us. I want to see how the work of accomplishing the subjectivity of Todd as a viable and recognizable subject occurs in the space of the interview.

In the conversation Todd comes across as a reflexive and communicative person with agency, letting me know that taking his CF medications is not up for negotiation, it is just an obvious thing to do. Even the Pep mask is an obvious thing to do when he is sick. But when he is well his body rebels against the boredom of the Pep mask. So, he cycles regularly to clear his lungs and his lungs let him know if he has left it too long between rides. He can soar through his cycling as a healthy cyclist with clear lungs.

I would like to look at the discursive work that I am doing as a genetic counsellor where I am seen to have the power as the interviewer, but within this analysis, I acknowledge that language can be complex in the way Lyotard suggested:

“Every utterance should be thought of as a move in a language game… ...So a move can be made for the sheer pleasure of its inventions. Great joy is had in the endless invention of turns of phrase, of words and meanings” (Lyotard, 1984, p. 10).
In this language game between us, I suggested to Todd that he should be using the Pep mask as a form of self-care. When I do this I am caught in the dominant discourse of CF, whereby it is my role to promote the use of medications on a regular basis. Todd takes this up but offers a different iteration by agreeing that it is useful only when he is sick. (Todd knows that when he is sick he cannot cycle, although this is not stated but implied, because with CF, when one is sick one is unable to get enough oxygen for exertions of any kind).

When Todd mentioned cycling I immediately suggested competitive cycling, which I approved of, and I wanted to add competitive running. At this point, I am caught up in ‘prescribing’ exercise, but Todd declines the invitation to include competitive running. In this very brief encounter we illustrated that in language games we can often say less to mean more and more to mean less. The individual speaker is no longer in control of what language ‘is made’ to do when they speak (it). We set in motion an endless interplay between the visible and utterable, since we rarely say what we see and seldom see what we say.

Todd can create a vivid image of himself out on the road clearing his lungs with very few words. Similarly, he can create an image of himself as sensible and competent, also with very few words. This illustrates the power of performativity whereby the agency of the subject can come into being through their take-up in language, as well as in the dialogue with the interviewer.

Foucault takes up this theme when he says,

“the potential for the utterance to perform meanings other than the ones that are stated is the danger […]… what is so perilous, then is the fact that people speak, and that their speech proliferates…” (Foucault, 1972, p. 216).

Foucault’s statement suggests that speech is indeterminate in its range and that ‘dangerous’ possibilities are performed beyond the individual’s intention.
While my research makes visible the performance of agency and difference in relation to the apparent inevitabilities of CF discourse, I am not claiming that the research participants simply intend or ‘will’ this difference, any more than I claim they are passive victims of discourse.

**Quan’s story**

There is a similar dynamic in my conversation with Quan. I knew Quan, another of my participants, from his visits to the clinic. I believe that he managed his life around CF well. He had very few admissions to hospital for ‘tune ups’. The discursive work I am trying to do in this interview is to get a sense of how Quan managed to stay healthy. I wanted to know what different things he may be doing compared to the other young people in my care.

*Monique:* Okay. Tell me about some of your interests at school.
*Quan:* At school I’m in the band, I play trombone.
*Monique:* And do you play anywhere else besides at school?
*Quan:* No.
*Monique:* And you enjoy that?
*Quan:* Yeah.
*Monique:* Are you really good at it?
*Quan:* Well I guess, I’ve only been playing for two years.
*Monique:* So the fact that you chose the trombone wasn’t because it was good for your lungs.
*Quan:* Kind of, it was a little bit, but mostly because I like it.

My question had strong constitutive undertones in that I suggested that trombone playing is good for his lungs. (The act of playing the trombone means air is held in the lungs and released in a controlled manner sometimes with more force than normal breathing. Playing any wind instrument has the capacity to control the Fev1, which is the forced expiratory volume of air in the lung at any one breath. Varying the amounts of air in the
lungs is a powerful exercise in strengthening the alveoli muscles as well as clearing the lungs.) So I implied that he is only playing the trombone because it is good for his lungs. But Quan only partly accepts being positioned as such, choosing instead to say that he does it because he enjoys it. Quan’s agency lies not in denying the CF but in defining his activity as only partly to do with CF and primarily to do with pleasure. He plays because he wants to, not because he has to. I address him in terms of his CF and he replies in terms of normal pleasure.

7.5 Performativity a response to the burden of normality

In *Bodies that Matter* Butler discussed ‘performativity’ as a repetition of a ‘ritualized’ production that is undertaken in the face of prohibition and taboo. She questioned why some bodies are made ‘abject’ by regulatory norms (Butler, 1993). The bodies of young people living with CF are scrutinized by the regulatory norms of healthy bodies and thus made ‘abject’. Examples of this are narratives of how young people being teased, particularly at primary school, incites these young people to undertake ‘ritualized’ performances such as doing physiotherapy and taking medication in order to accomplish normality. I read this as a ‘burden’ for this group of young people because to accomplish normality for them requires working to attain the ability to breathe with clear lungs, which the rest of us take for granted. Young people living with CF work hard at accomplishing themselves as normal and in doing so they work on their bodies in ways that young people without CF are unaware of.

This concept of performativity also enables us to understand that language itself can be violent in the ways it can work in us and through us, not necessarily in ways that we are aware of, or how we intend.

In this conversation, I asked Quan about his experience at school in relation to his peers. My agenda was to know if Quan had been ‘picked on’ by his
peers because he had been categorized by CF, and how he dealt with this situation.

Monique. So did anything stand out for you at that time, did the kids tease you or ask you questions?
Quan: It wasn’t really teasing it was more like asking questions. Like why do you have to do that, sort of thing?
Monique: Because?
Quan: Yeah, because I am special.

I am now aware of the discursive work I was doing then, by taking up the language of violence, which Butler referred to (Butler, 1997a), to infer that Quan may have been picked on. I was mobilising the ‘norms’ of school behaviour, where children who are somewhat ‘different’ are teased. It can be seen here that Quan did not choose to participate in the discursive position I offered, because being teased at school would render his life non-viable. Instead Quan challenged the position I offered and said, no, it is not like that at all, it was more curiosity and asking questions, (and that is also the ‘normal’ state of things at schools within the classroom - you ask questions). Then he brought up his trump card, his performativity in the form of a speech act, by saying “I am special”. After his statement that he is special, I too came to recognise and acknowledge that he is indeed special. As Butler says:

One comes to ‘exist’ by virtue of this fundamental dependency on the address of the ‘Other’. One ‘exists’ not only by virtue of being recognized, but, in a prior sense, by being recognizable. The terms that facilitate recognition are themselves conventional, the effects and instruments of a social ritual that decide, often through exclusion and violence, the linguistic conditions of survivable subjects (Butler, 1997a, p. 5).
Shirley’s story

The burden in taking up the performativity of accomplishing oneself as normal is shown by my participants in taking on the CF discourse by inscribing therapeutic acts on their bodies in order to live as normal. In the following conversation, Shirley said she knew that she was different because, whereas her friends could go home from school to play sports in the park, she had to do her treatment before she was able to go down to the park to join the other young people at play. Unlike Todd and Quan, Shirley relies on treatment and defers exercise in order to stay healthy. Only after treatment can she run around.

Shirley:

I knew that I was different because when I went home I realised that they were so different because they played sports in the afternoon and stuff like that whereas I did all my treatment and then I got to go out and see my friends and stuff and go down to the park and just have a run around and all the other kids, they got to do it direct after school.

However, Shirley related that she had managed to constitute herself as normal by comparison to young people with learning difficulties. She achieved this through her performance of ritualistic regimes required by CF to pass as normal.

Shirley: Yeah, we have, like at my high school now, I just went to high school last year, they have children with learning difficulties so like people are kind of like mean to them, which I think is really slack, but they’re not to me because I look normal and I talk normal and I just do my school work and things.
Shirley’s talk stressed the importance of normality and her work at maintaining it by remaining vigilant at school and doing her school work, managing her body and her voice to fit in with the norm so as not to draw unwanted attention to herself. The complexity of performativity is revealed in the contradiction that Shirley both ethically objects to the ‘othering’ of children with learning disabilities, yet relies on their abjection in order to constitute herself as ‘normal’.

7.6 Performativity as subversion of the medical discourse of CF

This section of the analysis centers on how Butler links performativity to the Althusserian concept of the ‘linguistic condition of survivable subjects’ (Butler, 1997a). Within this notion, performativity mobilizes speech, which, for the young people, becomes a process where they are able to both accept the terms of the medical discourse within which recognition is bestowed, and at the same time subvert it so that they are not totally overwhelmed by its dominance.

I now turn to the questions I asked my participants about their encounters with the CF clinic. I wanted to hear their experience of how the care they received or procedures they underwent may hurt them and / or otherwise affect them.

In this section of my analysis, I refer to two procedures commonly carried out on young people living with CF because of the need to deliver long or short-term antibiotics to their venous circulatory system. There are two types of access to the venous circulatory system: the peripheral cannular and the porta-cathe or central line. The peripheral cannular is a short-term device lasting two to four days. Porta-cathes are semi-permanent fixtures sited near the right atrium of the heart for intravenous drug delivery. A porta-cathe can be left in the body for long periods, needing a heparin flush every month to maintain patency. It has to be inserted under very strict sterile conditions in
an operating theatre. Young people who need regular intravenous drug treatment are usually given a semi-permanent site for drug delivery, as it eliminates the need to insert a peripheral cannula that has the disadvantage of being re-sited every second day to reduce risk of phlebitis.

**Todd’s story**

This is a conversation I had with Todd about cannulation\(^{14}\). I have been a children’s emergency nurse for over four years, and understand that cannulation amongst ‘normal run -of-the-mill’ young people in the emergency department (ED) remains a huge issue. Cannulation is known to be a very painful procedure. We provide pain relief such as creams and even Nitrous oxide gases for analgesia during this procedure.

*Monique:* If, umm, can you think of a time, something we usually talk about to kids is that, umm it’s like a bad time,

*Todd:* Hmm, hmm

*Monique:* When you have CF,

*Todd:* yep

*Monique:* What is it that made it worse for you, what people say or do, we’re saying, a time when you’re going through a bad time with CF, somebody just had to say or do something, it could be the nurses doctors hospitals GP even your own relatives, that doesn’t help your management of CF

*Todd:* No one sort of said anything abrasive, that I can really ever remember,

*Monique:* Even action? ’cause a lot of the kids said that the cannulation is probably the worst thing in hospitals...

*Todd:* Oh that’s what they hate the most?

\(^{14}\)Cannulation is a procedure where a needle is inserted into a large vein in order to obtain temporary access to the venous circulatory system for the delivery of medication/ blood products, which bypass the portal system allowing for therapy that is more effective.
Monique: yes, (laughs) ’cause it’s their complaints, of a lot of the younger doctors.
Todd: (laughs) yes?
Monique: Can’t cannulate,
Todd: Yes, oh, they’re hopeless, yeah, I’ll rather do it myself (laughs)
Monique: (laughs) you sort of didn’t have anything like that, sort of situation?
Todd: Oh yes, I’ve had my share of idiot doctors who can’t cannulate, and stuff, but that’s just part of them you know.
Monique: Does that cause, umm upset for you? You’re already hospitalised.
Todd: Yea I just don’t really care too much, like I mean I don’t, love it, but its just part of life, so you just, it doesn’t matter.

Analyzing the interview as a performative, I was positioning Todd as possibly having a negative attitude towards hospitals, where inexperienced doctors are permitted to carry out multiple cannulations, miss veins and inflict pain. Todd agreed that he had come across experiences of bad cannulations, but he refused to accept the position I offered him and to join in the condemnation of bad practice. Instead, he dismissed it and said that it is all just part of life for him and not a huge issue. Todd doesn’t deny the negative side of treatment, but he normalizes it - it is not worth talking about or focusing on, presumably since that would lend too much weight to a positioning as an abject CF sufferer.

Shirley’s story

In this next interview with Shirley, I asked her to tell me about the experience of her hospital stay. Shirley told her story of the medical discourse of patients having fewer rights than doctors and nurses. She made it clear to the medical cohort that she refused to be subjected to unnecessary pain.
She wanted to be treated as a normal person with normal needs of being allowed appropriate levels of pain management during her hospital stay.

Shirley: [...] like when I was sick, I had to have a cannula change every second day [...] I had a cannula and the nurses were putting the antibiotics through at 100 mils an hour and it really hurt, and even when we told them no higher than 60 mils in the middle of the night when I wasn’t awake [...] I woke up with pain all through my wrist and then I realise oh, what the hell is this, going at 120 mils for and they go, our protocol, [...] and I made them change it, they weren’t very helpful said its just protocols they told me I have to have this much saline at this many mils to go over this much time. Some of the nurses were really nice, they got me ice and things to put on my sore wrist and they slowed it down [...] like mainly if they just listened [...] like when I complained to like, I didn’t really complain, I was just telling someone about it, and they went and told the head nurse, ... and the head nurse who was usually mean, goes, you know we would never hurt you and all that stuff [...] and I am like well how come you set it at 120 mils an hour and it really hurts

Shirley told of her admission for intravenous antibiotics to control bacteria that had colonized her lungs. When Shirley spoke about having a cannula, it meant that she had a peripheral line into her veins for delivering intravenous drugs. Having a peripheral cannula meant that Shirley did not need to have regular repeated intravenous drug treatment. Unlike many of the young people living with CF, she did not have a semi permanent site like a porta-cathe or central line (an external porta-cathe).

Shirley must have needed aggressive intravenous antibiotic treatment, because aggressive antibiotics can cause a burning sensation in the veins when delivered in too low a dilution or at too fast a rate. Aggressive antibiotics can cause pain or swelling to the veins due to irritation, thus
rendering the veins non-functional. The solution is to increase the dilution rate with normal saline, or to deliver it at a lower rate. The recommended rate of delivery for young people is 80-100 mils an hour. However, the rate may be varied, because the speed of delivery will not affect the potency of these antibiotics.

Shirley attempted to subvert the power of the medical discourse by negotiating with her caregivers that she did not want the antibiotics to run any faster than 60 mils per hour when she was asleep as the pain caused her to wake up. She tried to assert her rights to minimize pain during treatment. She said she was upset because her negotiations with the staff were not carried out as she had wanted. Shirley accepted the subjection of CF in her willingness to receive treatment, but wanted to maintain her agency in relation to how it was managed.

Her relationship with the hospital staff was situated within powerful medical discourses of doctors, nurses and patients (Parker, 1990). Within this therapeutic relationship, Shirley is being positioned as a ‘patient’ needing treatment and this gives the nurses the position of power in their delivery of care (Lupton, 2003). The nurses used their knowledge of ‘protocols’ - written guidelines for safe and effective delivery of intravenous drugs (Browne, Choong, Gaudry, & Wilkins, 1997), to position Shirley as one without rights. Shirley mentioned that she did not complain but spoke about the incident to her friends in the ward; whereby the message got reported to the head nurse whom Shirley described as a mean person. The head nurse spoke to Shirley in her position of power to justify what the nurses had done within a ‘caring’ paradigm when she said ‘we would never hurt you’, even though that was not Shirley’s experience. This example illustrates Butler’s argument that any speech act has the performative power to institute as well as close off meanings (Butler, 1997a).
The negative experience that Shirley encountered opened up other positive experiences that she called ‘caring nurses’, some of whom slowed down the rate of antibiotics and others of whom provided ice for her sore wrist.

Davies said that ‘poststructuralist discourse calls attention to the unmarked and the invisible’ (Davies, 1994, p.19). Some of the young people I spoke with embraced the type of performativity that appeared unmarked and invisible. Their talk and actions can be viewed as unremarkable, but with a poststructuralist lens I can read these practices as ‘(un)remarkable’ and as subverting the medical discourse. These are narratives where my participants are able to achieve the conditions of possibility for becoming ‘survivable subjects’.

**Todd’s story**

In this example, I asked Todd whether he looked for information about CF to help him make informed decisions about his condition.

_Todd: Umm I guess I like to have information, I always like to know where I am, where I am um, where I am at._

_Monique: Umm_

_Todd: Actually I might annoy the doctors, they say to you, oh you know you’re perfectly well, you’re perfectly normal, you don’t need to be like this sort of thing, but I like to know really where I’m at, and always like to know that I am on top of things, and everything is great._

_Monique: Yes,_

_Todd: And what detail and information like yeah, and I just find it a bit annoying with doctors cause they, see that you are a very well person._

_Monique: Umm hmm_
Todd: They make you think, that, because you’re so well you ought to just be grateful for that, and not try to be even better and better?
Monique: Yes
Todd: I just want to know, want to be better,
Monique: Yeah, yes,

Todd is a young man who works hard on his body to achieve normality despite living with CF. He wants to subvert the medical discourse which labels him as ‘sick’ because of CF. He said that despite CF he wanted to be on the top range of his health functions, to be as well as ‘normal’ people. He said that the doctors pointed out to him that he has remained as well as it is possible to be and that he should be thankful and not try to excel in his level of wellness. All Todd wanted was information to be able to remain well and continue to remain well. The medical discourse of CF expected the young people to retain a level of unwellness. Thus it is ‘normal’ for the discourse to undermine the positive action Todd wanted for himself.

7.7 Performativity as iterability

Performativity as iterability points to ways ‘norms’ are constantly repeated in constituting us as subjects (Butler, 2007). Young people living with CF wanting to remain healthy work on their bodies in iterative ways to achieve wellness. In the iterative process most of my participants seek information to manage their bodies to inscribe wellness, to become appropriately ‘normed’ (Davies, 2000).

Todd’s story

In this narrative I asked Todd what process he used to obtain information in order to attain wellness.
Todd: You are still interested, you want to find out but you can’t really ask people because they don’t see the point. So like on the net it is much easier. I look on the net or basically the Internet.

Monique: Yes.

Todd: I try asking doctors about things, but if it is not things that are relevant, if they think it is not relevant to you as a CF patient, they don’t really try to broach the subject such as life expectancy or organ transplantation. I am nowhere near organ donor stage, nowhere near it, it is years off, but doctors don’t really want to talk about it sort of thing.

Monique: Yes

Todd: I’m sure they don’t mean it like that, but they see you, compared to other patients and they, say you’ve probably, like, doesn’t have CF, but, I am always trying to get better and better and better, and I just want to know more information, and I feel a bit guilty asking the doctors sorts of things, cause I feel like they, are judging me saying look you’re 90% or whatever lung function, I don’t know what it is, why do you want to umm, you know why, why be, you know, be anal about it?

Monique: Yes, yea.

Todd: Yea, I find them annoying in that way, and I guess it will be nice to, have someone to talk to where you feel like you’re coughing up lots of blood, and you feel like an old person already, like you haven’t been able to exercise for a couple of months or whatever, and feel run down and you think, is there any hope of getting up there again and, you know is this the beginning or the end is this a slide down hill now because you know I feel so trashy, be nice to have someone to talk to who knew a bit about CF to give you a bit of encouragement and information.

Todd embodied himself as one who can be recognized as an autonomous CF subject. He talked about the struggle to make the doctors understand
that just staying alive is not his option. He wanted to work hard at his
constitution as a young man living with CF so that he can triumph over the
subjection of CF to become competent, healthy and well. He wanted to soar
through life with clear lungs (Butler, 1997b).

Todd’s performativity reiterates Butler’s theory of power. I see Todd as a
subject of power of the medical discourse and I also see Todd’s need to
subvert the medical discourse. Todd is able to eclipse the conditions of his
own emergence and ‘eclipses power with power’ in his talk about his
frustrations with the medical discourse inscribing him as ‘sick’. He takes up a
position of agency and resists that subordination by trying to become better
and healthier. Todd (re)iterates the medical discourse, and rather than
submitting to its knowledge, he resists its exclusionary practices, by gaining
access to knowledge usually reserved for the medical profession.

Fiona’s story

Fiona talked about her future differently to Todd. She saw the limitations of
CF restricting what she can and cannot do. Fiona used her subordination by
the CF discourse as a condition of possibility for a ‘process of self regulation’
(Butler, 1997b, p 18). Instead of seeking more information to stay fitter and
healthier, Fiona turns to reflexivity as a form of ‘self-incarcerating movement’
(Butler, 1997b, p 33).

Fiona: Because of CF it’s like looking to the future when my friends
are thinking about careers and having kids and things, like that […]
mine are like, OK, then, but how does CF affect this? Then you have
to sort of think, OK I want to do this, but you also have to realise that
CF is going to complicate things to some degree, you know so, so,
you still do the best you can with what you have!

I read Fiona’s acceptance of subordination to the CF discourse as a means
of reflexively turning against power with power. As Butler says,
‘subordination is the condition of possibility’. Fiona is able to reflexively take up the discourse of CF and build her own conditions of ‘possibility’ in planning her future (Butler, 1997b, p 10), by both making plans and recognising her limitations.

Anna’s story

Similarly, Anna performed an iteration of CF discourse by saying that she goes to hospitals every three months for treatment even though she dislikes the process. This narrative is another version of Anna taking on ‘subordination as the condition of possibility’ in order to live a viable life.

Anna: when I go into hospital, cause like I’m not home and I’m like an hour and a half away from home and I um get pretty depressed about my animals and my friends ... and um yea, every three months [...] I have to stay at Wagga Base Hospital, for two to three weeks, umm, I cannot stand it, um, um having blood taken and that, but I still go.

Butler stated that ‘one is dependent on power for one’s very formation’ (Butler, 1997b, p 9). I read that Anna is dependent on the power of the medical discourse, but she has also performed a different iteration of subjectivity by attending hospital but planning a ‘time out with her friend’ together in hospital, so they can still have fun (earlier interview). She could refuse the hospital admission, but she did not: instead, she took on the discourse of CF to become an appropriate subject of CF, thus achieving ‘health’.

7.8 A story about performativity

One day I was walking along the corridors of the hospital between delivering letters signed by the specialists. I was walking briskly when suddenly I was
stopped by a hug from someone behind me, Rosemary! One of the younger CF kids. There was a group of about six young people, all excited about something. I asked them what there were up to. (I knew that most of them had been admitted to hospital for routine ‘tune ups’). A chorus of answers came together laughing,

\[ \text{All six: we, we do you …} \]
\[ (\text{then one of them piped up}) \]
\[ \text{Katie: Do you want your nails done?} \]
\[ \text{Monique. Why?} \]
\[ (\text{and they all seem to want to answer together}) \]

\[ \text{All six: We-we’re beauticians!!!!} \]
\[ \text{Monique: Huh um um} \]
\[ \text{Katie: We’re fund raising for the CF Foundation, and…} \]
\[ \text{Liz: we’re doing the kids’ hair for one dollar.} \]
\[ \text{Emma: Some of us are cutting and painting nails for 50 cents.} \]
\[ \text{Michelle: And I’m doing make up and facial.} \]
\[ \text{Tom: and I do the boy’s hair with gel and spike them and the girls help me too.} \]
\[ \text{Anthony: I can’t do beautician so I um, um I get orders and, and appointments and money.} \]
\[ \text{All six together: And, and, and… (laughs)} \]

I could not hear myself think with all the laughter around me. These young people, who are routinely subjected to medical procedures, were playfully offering practices associated with the performance of normatively beautiful and healthy embodiment - and they were offering them to me!! I closed my eyes and a sense of joy spread through me. I thought to myself, these sick young people were bringing joy to other sick kids as well…how paradoxical was that. The image stays with me to this day. I can still see their laughing faces.
This last chapter of my analysis has discussed the subjectivity of young people living with CF and they way they constitute their subjectivity within, against and beyond the terms of the medical discourse. I have explored how these young people were able to mobilize speech to both accept the terms of the medical discourse and at the same time subvert it. The performative practices they take up allow for actions that are constituted within and constitutive of the discourse of accomplishing oneself as normal. These young people took up positions of submission and of struggle in order to enact the potential for a performance of personal agency and the constitution of viable lives.
CHAPTER 8

DISCUSSION, FUTURE DIRECTIONS AND CONCLUSION

8. Introduction

This study has explored the narratives of twenty-one young people living with a potentially fatal complex genetic disease called Cystic Fibrosis (CF). The majority of my participants were born in the late eighties and their parents were told that these young people might not survive past school age, yet they are now living into adulthood. They have lived a life of constant dilemma, balancing medical treatment with attempting to live a 'normal' life for young people. This concluding chapter is divided into three parts. The opening section of this chapter draws together the threads connecting the different parts of the thesis to show how they reflect the central issues of my study. Part two discusses what has been achieved by my research and how it may contribute to the understanding of young people living with CF. I conclude this chapter with discussions on the limitations of my study and suggestions for future directions.

8.1 Drawing together the threads

This study has contributed to an understanding of the predicament, and also the capacities, of young people living with CF. It has been important to research and lay out for the reader the history and current science of this condition, both to establish the compelling strength of the medical discourse of CF and to give a portrait of what these young people face in their daily lives.

Despite advances in medical treatment, there is still no known cure for this genetic condition. Continued survival is made possible with the aid of a daily
regime of medications and physiotherapy as well as a strict adherence to self-care practices such as good nutrition and adequate pancreatic enzymes. In addition, these young people face an early onset of chronic age-related conditions, with damage to their hearts, lungs, kidneys and livers due to continual use of medications required to stay alive. Although most young men with CF are believed to be sterile, young women face the possibilities of passing on their genetic condition if they produce any offspring.

Much of the published research utilises quantitative standardised scales to generate psychological measures of self-perception and social skills to conclude that older young people adjusted better than the younger ones, without telling us why. Other studies used another dimension called the Health-Related Quality of Life (HRQoL) scale, which created correlations, means and probabilities, enabling the detection of health changes, again without giving any insights into why and how this change takes place.

My study, in contrast, has contributed to an understanding of the ways young people living with CF negotiate their lives within the medical and discursive space of CF. My study enabled me to think beyond the limits set by medical discourse, in order to gain an understanding of how this group of young people were living their lives. To accomplish this understanding, I had to find alternative ways of gathering and making sense of my data. My research set out to provide a space for these young people to tell their stories of their lived experience. People make sense of their life experiences by narrating them (Freedman & Combs, 2002; McCabe & Peterson, 1991; Mitchell, 1981; Riessman, 1993; White & Epston, 1990). As Shotter puts it, ‘narrative is... the orderly ways of talking...[that] forms our way of accounting for and making sense of ourselves and our world...’ (Shotter, 1993, p. 35). A narrative approach to research interviewing was instrumental in conducting interviews in a manner that assisted the participants to mobilise meaning making in their world. However, the interviews I conducted with these young people did not always elicit “orderly ways of talking” or give rise to thick, rich
or coherent narratives. Nor did my questions predominantly elicit the problem-saturated narratives I had come to expect. Therefore, I turned toward a poststructural iteration of research methodology that enabled me to read apparently ‘thin’ or ‘incoherent’ utterances in terms of the discursive and relational strategies these young people adopt in order to make sense of their life.

Selecting young people as a group to interview was important because, within the dominant discourse of development, critical problems arise when children living with CF move toward adulthood. This is the time when they are expected to have difficulty complying with the strict and repetitive medical regimes necessary to keep them alive. One study found that compliance with medical therapies is particularly difficult during the adolescent years (Fitzgerald, 2001). In my own study, alternatives emerged to this notion of ‘non-compliance’. I found that, with maturity, came the need for increasing independence, and that these young people managed to take responsibility for their own health in diverse and creative ways. The ways in which young people living with CF manage to achieve this are explored in my three chapters of data analysis.

I have not searched for singular ‘truth,’ within this data. Rather I took up a poststructural understanding of subjectivity and used the method of discourse analysis to deconstruct my data. Discourse analysis embraces the social practice of the development and formation of subjectivity. The poststructuralist strand of discursive analysis regards subjectivity as constituted through multiple and unstable discourses.

This project has deviated from positivist traditional, conventional approaches to mainstream psychological research in several important ways.
Firstly, ‘truth’ does not pertain to the search for truth, but to an understanding of ingenious ways that young people living with CF talk about and perform their conditions of living.

Secondly, although CF is a medical condition and treated as such traditionally, this study situates CF within a psychological and social landscape in order to tease out its psychological and social connections. This form of research is innovative because CF has predominantly been framed within medical discourse. Moreover, while psychosocial approaches to CF have become common in the last decade, much of this research assesses psychosocial issues quantitatively within a normative model of human development.

Thirdly, the focus of this study centres on an understanding, through poststructural theory and narrative enquiry, of the narratives of lived experience of these young people within the discursive formation of Cystic fibrosis (Foucault, 1970). These methodologies elicited the specific and diverse ways that young people living with CF constitute their subjectivities and their relationships to living with CF.

My initial narrative and social constructive methodology enabled me to elicit stories of how these young people negotiated localised relations of gender, youth and class alongside the added burden of a chronic lethal disease. Poststructural analysis provided me with a way of reading these narratives in terms of the constituting of subjectivities, through, against and beyond the competing discourses of CF and normality. The exploration of the young people’s discourses of identity, through a theory of subjectivity, unearthed their creative processes and their performances of agency in relation to the discourse of CF.
Chapter Two elaborated on my data collection, inspired by my choice of using narrative epistemology. Data was collected from 21 young people over a sixteen month period using an interviewing process that allowed them to tell their own stories. The interviews took place in their homes, as I did not want the constraints of the CF clinic to influence their narratives. I then utilised a poststructuralist approach to analyse the dialogue, to enable me to see the complex interactions of multiple discourses, and the ways my participants managed to negotiate the slippage between constituting themselves through the medical regime and resistance to its totalising tendencies.

There was a tension in Chapter Three between a discourse analysis approach based on Foucault’s analysis of medicine, and the imperative to give an account of the history and advances of science on CF. This chapter provided the information and set the stage for the formation of the subjectivity of young people living with CF. It traced the CF mutation back to the three suspected carriers of the CF gene, namely, the Vikings, the Phoenicians and Alexander the Great and his army. I explained how the complexity of the gene manifested into an intricate genetic condition with multiple organ involvement, resulting in difficulty in coming up with a specific diagnosis and definition in the early years. Although the disease condition was known as long ago as 1904, it was not defined until the 1960’s. The discovery of the CF gene in 1985 sparked much interest in the prediction of a cure for CF. It was not known then that the CF gene could manifest into over 800 mutations. This history was important to the understanding of the prognosis of people living with CF, in that a cure in 2010 was still unlikely because of the very complex nature of this gene.

Chapter Four took up the poststructuralist concept of subjectivity in order to understand how these young people's ways of experiencing the self are constituted within competing discourses and complex relations of knowledge and power. In discussing subjectivity, I drew on the specific arguments of four
theorists whose work I found useful to cast light on my data analysis, namely, Michael Foucault, Valerie Walkerdine, Bronwyn Davies and Judith Butler. These theorists offered a conceptual framework that I could use to process the narratives of my participants. When I theorised their subjectivity, I took on the concept of positioning to identify the social location of my participants and how they become constituted in the medical discourse of CF. I was interested in how their subjectivity is located in language and through the discursive categories of their everyday talk.

8.2 The Data analysis

When I approached my data analysis in terms of an understanding of subjectivity, three themes became apparent: normalization, resistance and performativity. The central issue that emerged was how and what activity my participants took on to position themselves as having ‘livable’ lives within the discursive space constituted by CF. When I first conceptualized this project, I assumed that the lives of my participants would be deemed ‘unlivable’ on account of the daily rigid regime of physiotherapy, medications and self surveillance that has to be undertaken in order to remain alive. During the interviews with my participants, however, I was unable to detect any of the hopeless, sad stories I had expected to hear from them. My experience of working in the Children’s Emergency Department means that I expected my participants to take up subject positions as ‘sick’, ‘sad’ and ‘hopeless’. From my experience and positioning within the clinical setting, I expected a concentrated infusion of problem-saturated stories. I thought I would need to actively search for marginalized and subjugated alternatives. The data collected at these interviews was quite contrary to my expectations. I was a health professional and had nursed CF children for more than 15 years and my discourse was colored by medical perception. My perception of ‘health’ was to be free of ‘illness’. The young people’s stories vigorously challenged this binary.
Just as my positioning within discourse shaped my expectations of what kinds of stories my interviews would elicit, my position also inevitably shaped the kinds of stories the young people were willing to tell me. When I reflect on my position within the CF team in relation to my participants, the relative absence of sad stories can also be read as an effect of this positioning. Perhaps my participants perceived me as part of the medical surveillance as well as a researcher. They may have been less likely to tell me ‘sad stories’ because they want to constitute themselves and be recognized as ‘normal’ young people in order to escape this gaze. My research journey and the co-constructed nature of the interview can be seen as a part of the production of subjectivities. The young people’s stories allow the opening up of ‘possibilities’ beyond the medical discourse. Viewing it from a poststructural perspective, these kinds of stories (or any story) are not objectively ‘true’, but this is not the main objective of the study.

At the beginning of my research, I was understandably ‘subjected’ to the medical discourse about CF that dominated my working environment. However, my subjection to the medical discourse was not totalising, since, after all, where there is power there is always resistance (Foucault, 1980). I had taken up some ideas from narrative therapy in my practice as a genetic counsellor and was attracted by the radical social constructionist critique of the medical model (Lupton, 2003). However, I needed to reposition myself, in order to conduct this research. Firstly, my repositioning as a beginning researcher enabled me to escape from the immediate institutional pressures that shape clinical work. Secondly, I embraced poststructuralism as the theoretical framework for this thesis. These moves enabled me to be open to my participants as ‘speaking subjects’ with views quite different from those I expected to hear.

I noticed a tension within my research participants between subjugation and resistance to the CF the discourse. I approached the tensions in the
narratives of my participants in three main theoretical ways. Firstly I used and expanded on Goffman’s concept of passing in order to theorise these young people’s self-regulatory and normalising practices of living as if free from CF. Secondly, I used Foucault’s analytic of power, in which resistance is intrinsic to power relations, in order to reframe the notion of these young people as ‘non-compliant’. Finally, I took up Butler’s theory of performativity, in order to more fully understand how the tensions between subjugation and resistance are intrinsic to the formation of these young peoples’ subjectivities.

8.21 Goffman’s concept of passing - normalization

Goffman identified ‘passing’ as a normalising task, which I recognized as taken up by my participants in their acts of daily living. For these young people, passing as normal involved practices of self regulation and normalisation, as a means of refusing to have their bodies inscribed as living with the disease of CF and in order to be inscribed within the society’s norms. My participants chose to actively take up particular discourses as constitutive of a normality they recognised as appropriate, and valued. For example, although Fiona was inscribed as living with CF, she did not fully take up this categorisation; instead she repositioned herself by relegating CF to only one ‘part’, but not the whole of herself:

“but yeah it has always been a part of me but it is not what defines me sort of thing as a person...”

This study has contributed to my understanding that young people living with a genetic disease are, in an important sense, not necessarily less ‘healthy’ than the general population. They have managed to achieve ‘health’ through practising ‘an autonomous aesthetics of the self’ involving self-regulating activities. One of my participants, Eve, managed to overcome the constraints of CF and created apparently impossible possibilities, in her pledge to live a
‘normal’ life. She had been able to discursively dismiss the blighted gene of CF and replace it with ‘sporty genes’, and even became a select member of a representative team for netball in the Australian state of NSW.

The notion of being outside of the norm is implicitly refused by most of my participants in their pursuit to pass as normal. In their narratives, I detected the subtleties and complexities of the subjective positions they took up to render their lives livable. Some of my participants achieved this by not disclosing their genetic condition to their peers. Others managed to control the symptoms of the disease by a rigorous regime of medication, exercises and physiotherapy, because they refused the stigma of being judged as sick or defective. The normalization practices my participants took up enabled them to construct their own versions of ‘normality’.

8.22 Reconceptualising resistance

The concept of resistance within Foucault’s analytic of power expanded my understanding of those actions of my research participants that are usually farmed within medical discourse as risky and non-compliant.

My participants were able to construct themselves as ‘normal’ by using modes of resistance, in creative, discursive ways. Their ‘acts of resistance’, such as the imaginative way they took their medications, showed that their diverse ways of staying ‘healthy’ did not necessarily fit into the model of the medical norm. The medical norm expects these ‘sick’ young people to make medications and physiotherapy a daily requirement of their lives; otherwise, they are categorised as non-compliant. My research uncovers a slippage between the concept of resistance as ‘unhealthy’ non-compliance, and as a ‘healthy’ practice of resistance to the totalising power of the medical discourse. These young people’s resistance to being labelled ‘sick’ mediates between the strict regime of their treatment and their need to live a liveable life. My participants managed to work with the medical regime to stay
healthy and, at the same time, subverted this medical discourse. In this way, their lives did not get taken over by the discourse of CF.

My participants were able to open up a window for me to see what was invisible before I conducted this research. They enabled me to see that there is no ‘black or white’ in terms of compliance or non-compliance with medications. I have come to appreciate that these young people knew their bodies better than I could ever understand. They possessed intricate insider knowledge of their own bodies and they could adjust their medical regime to their own convenience. I found them to be responsible users of the medical regime, because through an ‘informed’ use of medication, in which ‘information’ comes not only from medical science but also from their own narratives of experience and identity, these young people are able to achieve ‘normality’. As Fiona explained:

Well, the doctors and nurses might disagree because I am just totally ignoring CF for a total day but yeah, for me I think it is, it is, not too detrimental to my health which is the main thing. Like I wouldn’t do it if I am really sick you know...

My young participants did not want the strict regime of CF to totally control their lives, so they took up the position of being able to decide their levels of ‘sickness’ according to their self-knowledge, and titrate their state of health to the need to medicate. This gave them some agency within the regulatory regime of CF through their acts of ‘to-be or not-to-be’ sick.

8.23 Performing the performative

Butler’s theory of performativity enabled me to draw together how my participants’ subjectivities are formed and performed, within and against the medical discourse of CF.
Through processes of performativity, my participants mobilized new possibilities for identity and subjectivity. The indeterminant character of language itself, and its performative power, allow for personal and social change to emerge from apparently fixed positions of struggle and conflict. My participants mobilized the performative power of language to constitute themselves as agentic subjects. Language became a discursive resource that allowed my participants to create difference, through taking up and narrating actions that were both constitutive and constituted.

One of my participants Todd, has taught me that ‘near enough is not good enough’ in the management of his disease condition. He has challenged my concept of the subjectivity of a person living with a genetic condition. I have learnt from Todd that for him ‘nothing is impossible’ as a young person who could soar through the landscape on his bicycle and clear his lungs. Todd’s story made me ask the question whether I was more “subject” to dominant medical discourses about CF than the young people themselves? I realise that sometimes I flip into the medical mode, but generally this research project has helped me to think poststructurally as a clinician. I am more aware of the complexities of how these young people take up or reject the positions offered by the medical discourse. Todd helped me realize that in young people’s dealings with CF there are possibilities as well as constraints. Through this and other examples, my study illustrates the way these young people managed to negotiate the constraints of CF and create possibilities for living a ‘liveable life’, rather than allowing their lives to be colonised by the CF discourse. This is the focus I take from Davies (1992). Like Davies I seek to understand how these young people living with CF can be both ‘subjects’ and ‘agents’. Within this view I understand these young people not as passively shaped by active structures such as their genetic disease, but rather as “actively tak[ing] up as their own the discourses through which they are shaped” (Davies & Banks 1992 p. 3). In this study I have not set out to seek true or to produce truth statements about the reality of young people
living with CF. Instead, I have regarded the young people’s narratives as discursive productions through which they make sense of their lives and take up a position of agency within and against competing discourses.

8.3 Part Two

Achievement of my research and its contribution to understanding the young people living with CF

My research has expanded knowledge and created awareness of how young people living with CF actively take up subject positions and discourses that optimise their experiences of ‘wellness’ and ‘normality’. This work has made visible the practices by which these young people both embraced and resisted medical discourse in learning to care for their genetic condition and live viable lives. The insights generated by this study could guide the medical providers of health to put in place a ‘future-proofing’ (Gerrity & Lyons, 2003) set of guidelines, which may enhance and encourage good health maintenance practices. Stanton’s study on survivors of breast cancer, for example, reiterated that there is a need to provide adaptive interventions for long term cancer survivors (Stanton, 2006). In the light of my research, health professionals would need to revise their attitude to the terms non-compliance and non-adherence. The need to take prescription medication has long been an issue that concerned health practitioners caring for people living with chronic illness, who perceived that the life-long need for intensive treatment of the disease process created a tendency to non-compliance/non-adherence (Llorente, Gracia, & Martin, 2008). This concern is so prevalent that the World Health Organisation has defined adherence as “the extent to which a person’s behaviour taking medication…[…] corresponds with agreed recommendations from a health care provider” (Sebate, 2003). Methods to

15 Future proofing describes the need to anticipate health guidelines acceptable and ‘user friendly’ to young people.
measure rates of adherence are nevertheless so varied that no one has come up with a ‘gold standard’ of measurement (McNamara, McCormack, McDonald, Heaf, & Southern, 2009). In my own study I have not attempted to measure rates or frequencies of non-adherence/non-compliance. Rather, I have sought to read instances of non-compliance/non-adherence through the lens of poststructural theory, as acts of resistance that interrupt the domination of the medical discourse of CF. A poststructural reading can make sense of non-compliance, which is reconceptualised as a necessary struggle within the ‘identity work’ the young people engage in to build for themselves liveable lives (Bottrell, 2007).

The acts of ‘non-compliance’ my participants engaged in are often circumscribed by their relationship with CF, rather than constituting a total rejection of the medical discourse. Most of the participants chose to actively and selectively use medication because it allowed them to feel ‘normal’. Normality for my participants was having clear lungs, which the rest of us take for granted. My participants usually mobilized routines of non-compliance when they felt well and ‘normal’. They did not constitute themselves as being always already ‘sick’. The young people in this study responded to the discourse of CF by taking it up on their own terms, rather than being oppressed by it. This ‘interpellation’ emphasises a form of power that depends on agency rather than coercion.

Within a poststructural understanding of ‘non-compliance’, it can be seen that my participants did not have to ‘do’ their medications all of the time, just because they have CF all of the time. (In fact, most of them do not ‘do’ CF all of the time, either.) The participants in this study used intelligent compliance rather than ‘mindless’ acceptance of the power of the medical discourse. This ‘intelligent compliance’ means they understood the function of the medications on their bodies. With this awareness, they were able to titrate their medications to suit their bodily needs and stay well. These actions emphasised the poststructural view
that a person is not passively socialised into the world, but is ‘interpellated’ into it. By actively taking up the medical discourse of CF, my participants ‘troubled’ the system and inserted their own meaning into it with intelligent compliance.

8.31 Seek the co-operation of the young people in devising plans

The next section will discuss ways of tailoring a ‘user friendly’ support system for these young people. One of the objectives that arises out of my research is a plan to devise a tailor-made support system that may help young people living with CF to achieve satisfying psychological and social health. I have consistently believed that these young people should be given the opportunity to enjoy the same psychological and social health as the general maturing population without CF. In the light of the research I have undertaken, I will need to relocate my initial vision of this support system to incorporate a recognition and mobilization of the discursive resources of young people living with CF.

To think beyond the limits set by medicine, I need to incorporate young people’s contribution as central to planning their care. My participants understand their own needs and the hurdles they encounter. I propose that in devising a support system we need the young people to be strongly involved in the conceptualisation and implementation of plans and ideas that they know will work. They are the people who know most about their “intrinsically ambiguous” and “intractable life conditions” (Karp, 1996, p.14). We are only able to devise a workable system if it is in tune with their needs and responsive to their existing ways of negotiating their lives. A system based purely on medical knowledge by ‘experts’ in the field would mean that such an approach may be “too narrow and tight”, and consequently not useful for people who need a “broader framework to find meaning in their lives” (Parker, 1999, p.145). The framework of poststructuralist thinking
incorporates both psychological and sociological aspects of care. From this perspective, each care plan should be written and reviewed with the young people to incorporate their ideas and decisions on assessments and implementation. Allowing them to have significant input into these plans will mean that young people have the power to shape a plan that is consistent with their wishes and capacities, and which addresses social and personal dimensions, as well as their medical needs. They will be more likely to feel a sense of ‘ownership’ and to incorporate these plans into their lives. It is also important where possible to incorporate young people’s families and friends into these plans, in ways that young people themselves indicate are supportive. As Wetherell states, people are dependent on others for self-definition; hence, identity seems to be emergent and co-constructed (Wetherell, Taylor, & Yates S, 2001, p. 186).

For many young people living with CF, as they get older, friends become the most important ally in their social world. As health professionals we need to know how young people define themselves and that living with CF does not define them. We need to assist young people to mobilize the support inherent in their practices of friendship, as well as in their practices of kinship. This suggests the limits of individual care plans, however carefully negotiated, and points towards the possibility of mobilising networks of young people in order to enhance the subjective and social possibilities for those living with CF.

8.4 Part three

The limitation of my study and future directions

I am a genetic counsellor working with the CF team, and as a member of this team, I am part of the medical discourse in which some aspects of my work are ‘privileged’ and others are ‘silenced’. Up until I embarked on this research, I was able to inhabit this medical discourse even while it subjected the young people I cared for to a ‘narrow and tight’ judgement. My positioning
within medical discourse inscribed some limitations to this research project from the outset. For instance, I was unable to engage in research that gave rise to understandings of why so many of the young people admitted to the Emergency department were self-harming. These young people who attempted self harm were categorised and put under the care of the Adolescent Mental Health Team (AMHT). At the outset of my research, I had not questioned this practice and therefore had not included these young people, having been told by the CF team that I may compromise the treatment they were undergoing under the AMHT if I had included them in my study. I propose that a future study may be able redress this issue.

8.41 Young people living with CF and mental health

One major limitation imposed on my research by the CF team is the constraint to interview only the emotionally healthy group of young people. As stated above, I did not have access to the small population of young people living with CF who were under the care of the Adolescent Mental Health Team (AMHT). It would be another enlightening research project to compare the narratives of my participants to those of the young people under psychological treatment in the care of AMHT. The aim would not be to look for true or false answers in relation to the variable effects of CF on young people’s mental health, but to understand what different discourses and processes of subjection each group takes up in their strategies for living.

8.42 Adults living with CF

Continuing research in relation to adults living with CF would be informative and would be a viable direction for future research. Adults could be expected to tell fuller and more longitudinal narratives than my young participants, thereby contributing further to the narrative resources about living with CF. Moreover my young participants will one day be adults as well.
Retrospective narratives in which adults living with CF reflect on their experience as young people would provide valuable information and would help in current care planning for young people.

8.5 How much will my thesis advance professional discussion?

My research has cast light on the normalizing practices of young people living with CF. These are what Frank called ‘restitution narratives’, which reflect the natural desire to stay well (Frank, 1995), and to be treated as ‘normal’. One of my participants said to me one day, “I am not ‘sick’, I have just got CF”. These narratives bring into focus for me young people’s ways of ‘passing-as-normal’. In their quest for ‘normalization’, my participants engaged in acts of resistance thereby refusing to accept being ‘territorialized’ totally by the medical discourse of CF. Health professionals practice surveillance over my participants by reviewing their blood test results and lung function levels, within a moralistic framework that often takes on the implication of guilt if non-compliance becomes an issue. To move professional discussion along lines where the young people living with CF can be more fully understood, I believe that health professionals will have to be ‘socialised’ into understanding and taking into account young people’s need for agency.

Young people’s practice of agency is illustrated in their performance of ‘technologies of the self’, where they take up the position of self-surveillance to intelligently use their medication to pass as normal. As professionals, we need to understand that the selective and intelligent use of medication should not moralistically be judged as non-compliance/non-adherence. We need to think outside the square.

Medical science is not, however, intrinsically opposed to young people living with CF taking up agency, and medical technology can extend the possibilities for these young people to challenge normative discourses about their lives. My
literature search has revealed a surgeon who writes critically about medical discourse in relation to CF.

In his recent work, Gwande discusses a conversation he had with a young doctor living with CF (Gwande, 2007). In their discussion, they suggest that the profession needs to examine its own ‘performance’, and to look for the opportunity to examine its own change by recognising inadequacies and seeking out solutions. Gwande recounts the story of a CF specialist, Warwick, who engaged with the young people he cared for to take on ‘technologies of the self’, as a form of rebellion to outdo the ‘norm’ of CF care. Warwick also understood the difficulties of the daily manual chest physiotherapy for lung hygiene. So, he invented a mechanized chest-thumping vest for his CF clients to wear. This device has since been clinically tested, and use by 45,000 people living with CF in America. This physician managed to take up the position of understanding rather than surveillance and in doing so turned his CF clinic in Minnesota into a respected world class clinic boasting the oldest surviving CF client at age sixty-seven (Gwande, 2007,p.225).

8.6 Conclusion

This thesis has argued that, in seeking to understand the lived experience and narratives of young people surviving CF, it is necessary to take into account the personal and subjective dimensions of how medical discourse is taken up and resisted by these young people. Initially, I argued that studies using objective instruments, such as Health Related Quality Of Life (HRQOL) Scale and the Treatment Adherence Rating Scale (TARS), cannot get to the root of why young people living with a chronic disease practice ‘non-compliance’. Beginning with a narrative interview methodology, I was surprised when the stories narrated by the young people in my interviews defied my expectations that their stories would be dominated by distress. Subsequently, I explored the narratives and subjectivities of these young people through three main theoretical constructs:
normalisation or ‘passing; resistance to power; and performativity. This approach to the data made visible the inventive and selective ways in which young people shaped and enacted their lives, relationships and selves, within and against compelling discourses associated with medicine, adolescence and chronic illness. Thus, my study has shown the value of thinking beyond the limits of medical discourse: into a more balanced and holistic way of understanding and accepting the stories, practices and subjectivities of young people living with CF.
References:


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Appendix one

The weekly CF Clinics

The CF Team consists of a multidisciplinary team of a medical director, six medical specialists, one gastroenterologist, a psychiatrist, two clinical nurse consultants, one clinical nurse co-ordinator, two research nurses, two lung function technicians, two nutritionists, one pharmacist, two physiotherapists a pathologist assistant and a social worker. Unlike other CF clinics this CF team does not have a specific genetic counsellor at their clinic. I was there on a need basis only and my main role was to co-ordinate the multi-disciplinary team for the smooth running of the clinic.

The team meets twice weekly on Tuesdays to review previous clinic visits and plan for the next clinic. A planned research meeting is incorporated monthly into the Tuesday meetings where a speaker is invited for discussion regarding new developments in the research field.

There are on average four Wednesdays a month, the first Wednesday of the month is devoted to the infant group of pre five-year old CF children clinics. The second Wednesday is set-aside for those of school age to seven years olds. The third Wednesday remains the adolescents’ clinic day, and the fourth Wednesday accommodated CF children from 7 years old to the early teens. On rare months when a fifth Wednesday occurs there is no clinic day. The CF clinics are arranged in this order in the belief that the younger CF members are less likely to colonise antibiotic resistant fauna. By separating the age groups the vision was to minimise cross infection, particularly respiratory fauna, which are wind borne and can be contagious. However what was not taken into consideration was that, when there were multiple siblings in the household with CF, it was inconvenient for the family to attend separate CF clinics, especially the out-of-town population.
Appendix two

Interview Questions

A. Questions of the Influence of CF in young peoples lives
   1. How has CF affected you and shaped your life?

   Prompts:
   When were you first aware that CF was in your life and not in others’ lives?
   Has the influence of CF changed as you grow up?
   In what ways has it changed or not changed?

B. Questions on the ways young people manage the presence of CF
   2. What would people close to you say about the way you manage CF?
      What would they see you doing to manage?

   Prompts: self-care practices, conversations to assist management, such as asking for help, advice, or talking to peers, friends etc.

   Are there ways you deal with CF that they would not know about?

   Prompts: doing searches on the net, self-talk, reading lots of books, living as normal a life as possible but knowing the limitations of this, channelling themselves into sports or activities they can manage.

C. Questions to elicit from them, what is helpful and not helpful to them in this management
   3. Can you think of a time when somebody said something or did something that really helped you take charge of CF?
      a. what was it?
      b. If you cannot remember one, could you imagine one?
      c. What do other people do or say when they relate to you that helps you?
      d. What do they do or say that does not help you
Appendix three

PARTICIPANT INFORMATION SHEET

LIVING AT THE EDGE: Adolescents surviving Cystic Fibrosis.

Investigators:
Monique Dyson, PhD student UWS Nepean
Registered nurse Emergency Department.
Ph. 9613 0048 (h) 9845 0000 (w)

Supervisor:
Dr Hilary Byrne Armstrong
Regional Head, Dept of Psychology.
Penrith Campus
University of Western Sydney
Ph. (02) 4736 0230, or, 0412 1346 00

We would like you to consider participating in a research study we are conducting in understanding the lived experience of adolescents growing up with Cystic fibrosis.

What is the study about?
The study is about finding out how adolescents are coping with growing up with Cystic fibrosis, how it is impacting on their maturation, and planning for the future.

Who can participate in the study?
Children living with Cystic fibrosis between the ages of 15 and 18 years old.

What will the study involve?
Just one hour of your time in the form of an audio taped dialogue/narrative, at a date, time and place specified by yourself.

Are there any benefits for me participating in the study?
The benefits will be an understanding of the needs of yourself, and the possibility of providing resources which may assist you with the difficult stage of transition into adulthood.

Other information
The information collected from this study will remain confidential, and the data will be stored in a locked cabinet at the supervisor’s office in the premises of the University of Western Sydney, Penrith Campus.

What if I have any questions or concerns about the study?
If you have any concerns about the conduct of this study, please do not hesitate to discuss them with my supervisor Dr Hilary Byrne-Armstrong, or with Anne O ‘Neill, (Ph: 9843037), the secretary of the Ethics Committee which has approved this project.

Participation in this project is voluntary and if you decide not to take part or decide to withdraw at any time, this will not otherwise affect your care at the New Children’s Hospital.

This information sheet is for you to keep. We will also give you a copy of the signed consent form.
Appendix four

PARENTS AND ADOLESCENT CONSENT FORM

Experiences of living with Cystic Fibrosis (CF)

Investigators:

Monique Dyson, Registered nurse Emergency Department, Ph. 9613 0048 or 9845 0000

Dr Hilary Byrne Armstrong, Dept of Psychology, Penrith Campus, University of Western Sydney

Ph. (02) 4736 0230, or, 0412 1346 00

I have read and understand the Information Sheet, and give my consent to participate in this research study, which has been explained to me by:

___________________________________________________________________________________

I understand that I am free to withdraw from the study at any time and this decision will not otherwise affect my treatment at the Hospital.

NAME OF ADOLESCENT:
__________________________________________ (Please print)

NAME OF PARENT OR GUARDIAN:
__________________________________________ (Please print)

SIGNATURE OF PARENT OR GUARDIAN:
__________________________________________ Date: ______

NAME OF WITNESS:
__________________________________________ (Please print)

SIGNATURE OF WITNESS:
__________________________________________ Date: ______

NAME OF INTERPRETER:
__________________________________________ (Please print)

SIGNATURE OF INTERPRETER:
__________________________________________ (Please print)
Appendix five

Notification of ethics approval to chief investigators

1) The Children’s Hospital at Westmead

2) University of Western Sydney