

Volume One

**The Nature and Prevalence of Eating
Disorders and Eating Disturbance in
Adolescents with Cystic Fibrosis.**

JOANNA SHEARER

D. Clin. Psy 1999-2002

University College London

ProQuest Number: 10013348

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest 10013348

Published by ProQuest LLC(2016). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code.
Microform Edition © ProQuest LLC.

ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

CONTENTS

Page Number

Abstract	7
Acknowledgements	9
CHAPTER 1:	
INTRODUCTION	
Overview	10
Cystic Fibrosis	
The Prevalence of Cystic Fibrosis	10
Genetics	12
Symptomatology	12
The Diagnosis of Cystic Fibrosis	14
The Treatment of Cystic Fibrosis	14
Eating Disorders and Eating Disturbance	
Eating Disorders	17
The Diagnosis of Eating Disorders	18
The Prevalence of Eating Disorders in Adolescence	19
Atypical Eating Disorders	21
Eating Disturbance	22
A Continuum between Eating Disorders & Eating Disturbance	23
The Prognosis of Eating Disorders	24
Risk Factors associated with developing an Eating Disorder	27
Why Adolescents with Cystic Fibrosis might be at risk of developing Eating Disorders/ Eating Disturbance	36
Evidence of Eating Disturbance in Adolescents with Cystic Fibrosis	41
Evidence of Eating Disorders in Adolescents with Cystic Fibrosis	42
Comorbidity: Distinguishing Eating Disorder Symptomatology from Cystic Fibrosis	48

Page Number

INTRODUCTION Continued

A need for further research	49
The current study	50
Research Questions and Hypotheses	51

CHAPTER 2:

METHOD

Overview	52
Ethical Considerations	52
Recruitment Procedure	52
Participants	53
Data Collection	54
Measures	56

CHAPTER 3:

RESULTS

Overview	64
Demographic Information	64
<u>Eating Disorders</u>	
Research Questions and Hypotheses	71
<u>Eating Disturbance</u>	
Research Questions and Hypotheses	79
<u>Further Investigations</u>	99

Page Number

CHAPTER 4:

DISCUSSION

Summary of Results	102
<u>Research Questions and Hypotheses</u>	
Eating Disorders	104
Eating Disturbance	111
Further Investigations	120
Limitations of the Present Study	121
Implications for Future Research	125
Implications for Clinical Practice	127
Conclusion	129

CHAPTER FIVE:

References	131
------------	-----

Page Number

APPENDICES

1. The DSM-IV Criteria for Anorexia Nervosa	158
2. The DSM-IV Criteria for Bulimia Nervosa	160
3. The DSM-IV Criteria for Eating Disorder Not Otherwise Specified	162
4. Letters confirming Ethical Approval	164
5. Extracts from Ethics Applications to obtain non-participant data	168
6. Invitation to Participate: Participants	171
7. Invitation for Child to Participate: Parents/ Legal Guardians	174
8. Participation Form	177
9. Great Ormond St Hospital Assent and Consent Forms	179
10. The Royal London Assent and Consent Forms	182
11. Demographic and Health Status Form	187
12. Descriptions of the Harter/Hoare Self-Esteem Questionnaire sub-scales	189
13. The Harter/Hoare Self-Esteem Questionnaire	191

LIST OF TABLES

Page Number

1-1	Summary of physical complications associated with early onset eating disorders.	25
3-1	Demographic information of participants from two Cystic Fibrosis Centres	66
3-2	Demographic information of participants according to gender	68
3-3	Self-esteem scores of participants	69
3-4	Comparison of participants with non-participants	70
3-5	Nature and prevalence of Anorexia Nervosa	72
3-6	Nature and prevalence of Bulimia Nervosa	74
3-7	Nature and prevalence of Eating Disorder Not Otherwise Specified	75
3-8	Sub-threshold criterion scores for Anorexia Nervosa	81
3-9	Sub-threshold criterion scores for Bulimia Nervosa	83
3-10	Sub-scale category scores obtained on the CEDE	89
3-11	Global sub-scale category scores obtained on the CEDE	92
3-12	Demographic differences between those with and without Eating Disturbance	94
3-13	Differences in self-esteem between those with and without Eating Disturbance	96
3-14	Global sub-scale category score differences between those with and without Eating Disturbance	98
3-15	Assessment of associations with Eating Disturbance	101

LIST OF FIGURES

Page Number

1-1 A multi-dimensional model of the development of an Eating Disorder

35

ABSTRACT

This study surveyed the nature and prevalence of eating disorders and eating disturbance in adolescents with Cystic Fibrosis (CF). CF is an incurable, genetic disorder that is associated with respiratory and digestive problems and consequently inadequate nutrition and poor growth. Good nutrition is considered vital as low weight has a detrimental and potentially fatal impact upon health status in the CF population.

Research has consistently revealed eating difficulties throughout childhood in the CF population but few studies have examined formal eating disorders or eating disturbance in adolescents with CF, despite clear evidence to support the notion of a developmental continuum between eating disturbance and eating disorders in the general population. Previous studies appear to have a number of methodological limitations, particularly the use of self-report measures, which are unable to provide formal diagnoses, making it difficult to draw any firm conclusions. Because adolescents with CF appear to experience many of the risk factors that have been documented within the eating disorder literature and because eating disorders pose a particular threat to their longevity, this issue requires clarification.

This study aimed to improve on previous research designs by utilising a semi-structured interview designed to assess and diagnose eating disorders in an adolescent population. 55 participants aged between 11 and 17 years completed the Harter/Hoare Self-Esteem Questionnaire and the Child Version of the Eating Disorder Examination. Demographic and health status information were obtained for all participants and for those who did not

wish to participate.

Results revealed that none of the participants met all of the criteria for either Anorexia Nervosa or Bulimia Nervosa. However one male participant met the diagnosis for Eating Disorder Not Otherwise Specified. Eating Disturbance appeared to be prevalent within this sample, irrespective of whether or not puberty had been reached. 16% of participants, some of whom were under weight, were attempting to lose weight or avoid weight gain whilst the majority of the sample described concerns relating to their body shape or weight. There were no significant differences in gender or health status between those with or without eating disturbance but there were significant differences in self-esteem and in shape and weight concerns.

Results reveal that both pre and post pubertal male and female adolescents with CF have eating disturbance, which does not necessarily reflect their weight or their health status. This sample may be at risk of developing eating disorders in the future, particularly when they gain more independence and their eating is not monitored as closely by their parents. Patients appear to develop eating disturbance from a young age, which suggests that CF centres should attempt to work systemically to facilitate healthy eating attitudes and behaviours in patients from an early age.

ACKNOWLEDGMENTS

I would like to thank Mandy Bryon, Cathy Creswell, Chris Barker and Pasco Fearon for their expert advice and encouragement throughout this study. I would also like to thank the Cystic Fibrosis teams at both Great Ormond Street Hospital and The Royal London Hospital for imparting their knowledge and experience. My thanks also go to all of the participants who gave up their time to take part, without whom this study would not have been possible. Finally I would like to thank my family and Michael who have provided invaluable support throughout.

CHAPTER 1

INTRODUCTION

Overview

This study examines the nature and prevalence of eating disorders and eating disturbance in adolescents with Cystic Fibrosis (CF). Low weight has a detrimental and potentially fatal impact upon health status in the CF population (MacDonald, 1996). Consequently patients are prescribed a nutritious diet that is high in both protein content and calories. Whilst eating disorders and eating disturbance represent a significant public health concern, particularly amongst adolescents, any disturbance related to eating within the CF population could reduce an already diminished life expectancy further. Such difficulties therefore require identification and treatment.

This chapter will describe CF and then examine the nature and prevalence of such eating problems in the general adolescent population, highlighting factors that might play a role in their aetiology. The rationale for considering why adolescents with CF might be at increased risk of developing such problems will then be presented, followed by a description of previous research studies that have focussed upon this topic area to date and their limitations. The research questions and hypotheses will then be introduced.

Cystic Fibrosis

The Prevalence of Cystic Fibrosis

CF is the most common, lethal genetic, hereditary disease in the United Kingdom, affecting approximately one in 2,500 live births (Super, Barnes & Greig, 2001). CF

affects males and females in equal numbers (Green, 1996). It is a complex autosomal recessive gene disease and thus an individual must inherit one defective copy of the CF gene from *both* parents to have CF. If an individual only inherits one copy of the CF gene from one parent, s/he is a carrier and is therefore asymptomatic. It is estimated that one person in every 20 in the United Kingdom is a carrier (Family Resource Centre, Great Ormond St Hospital, 1996). Each time two carriers conceive a child there is a 25% chance their child will have CF, a 50% chance that the child will be a carrier and a 25% chance that the child will be a non-carrier. People with no family history of the disease have a 1 in 25 chance of being carriers so the general risk of having a child with CF is 1 in 50. A couple where one member is a carrier whilst the other has no family history are 12 to 16 times more likely to have a child with CF (Super et al., 2001). It is currently estimated that CF is approximately six times more prevalent in the Caucasian population than it is in other ethnic populations (Online Encyclopedia, 2000). These statistics reveal that CF is a relatively common disease.

Currently there is no known cure for CF. Thirty years ago most babies born with CF died in early childhood, but advances in the diagnosis and treatment of this disease have significantly improved its prognosis, despite the significant clinical variation in symptomatology and severity (Prasad, Tannenbaum & Mikelson, 2000). CF is no longer a disease associated exclusively with children. It is currently estimated that more than 60% of babies born with CF reach adulthood (Online Encyclopedia, 2000). Indeed, in 1993 it was estimated that the millennium would see over 6,000 patients with CF in the UK, half of whom would be adolescents and adults and that those over 15 years of age would increase by approximately 120 per year (The Clinical Standards Advisory

Group, 1993). A mean life expectancy of 30 has been documented in some CF centres (Medical News, 1984), whilst others estimate that those born with CF in the 1990's and in receipt of optimal care may reach their 40's (Elborn, Shale & Britton, 1991). CF is a progressive disease and thus, whilst young children generally do well, health tends to deteriorate with age, despite good adherence to treatment (Eiser, Bozhina, Hiller, Havermans & Billig, 1995).

Genetics

The first gene for CF was isolated in 1989, and currently approximately 500 variants have been described (Family Resource Centre, 1996). Differing mutations confer a mild, moderate or severe presentation (Family Resource Centre, 1996). CF is caused by a defect in the gene, located on chromosome seven, which is responsible for manufacturing cystic fibrosis transmembrane regulator (CFTR), a protein that controls the flow of chloride ions into and out of certain cells. Since the isolation of this gene, it has been possible to identify the precise disease-causing mutation in the majority of cases.

Symptomatology

In healthy people CFTR forms a channel in the plasma membrane through which chloride ions enter and leave the cells lining the lungs, pancreas, sweat glands and small intestine. In people with CF, malfunctioning or absent CFTR prevents chloride from entering or leaving cells, resulting in the production of thick, sticky mucus, which clogs ducts or tubes within the above organs, thus affecting several major organ systems, primarily the respiratory system and the digestive system, but also the liver and the kidneys. The effects of this within the respiratory system are frequent bacterial lung

infections, as the mucus blocks airways, thus predisposing the lungs to infection. The mucus also impedes natural infection-fighting mechanisms. Lung infections are the primary cause of mortality and morbidity as they lead to progressive lung damage and ultimately respiratory failure and premature death. Chronic lung infections often lead to poor appetite, difficulty maintaining weight or indeed weight loss and poor growth. Thus patients with CF are particularly slight for their age and often have short stature.

Within the digestive system, the accumulation of mucus within the pancreatic ducts prevents natural, pancreatic digestive enzymes from reaching the intestine to participate in the break down and digestion of food. This leads to pancreatic acinar tissue damage, resulting in the progressive loss of pancreatic function by fibrosis and fatty replacement, which are the characteristics of the pancreatic lesion in CF. Approximately 85% of CF patients have such severe loss of functioning pancreatic acinar tissue that the inadequate enzyme secretion results in inadequate absorption of nutrients from the intestinal tract. This results in the incomplete digestion of food, causing unsatisfactory nutrition and therefore poor weight gain and poor growth. Such patients are known to be 'Pancreatic Insufficient'. Poor nutritional status also results in vitamin deficiency so that, when infections are present, particularly in the chest, the patient is less able to effectively fight the infection due to his/her malnourished state. Malnutrition consequent to malabsorption has been found to have significant deleterious effects upon pulmonary function, including, reduced ventilatory drive, impaired pulmonary muscle function, reduced exercise tolerance and an altered pulmonary immune response (Dalzell et al., 1992). Approximately 15%-20% of patients retain sufficient functional acinar tissue to digest and absorb nutrients normally. However a significant proportion go on to develop

pancreatic insufficiency, as they get older due to continual or recurrent ductal obstruction.

Further features of CF include multi-organ abnormalities such as liver cirrhosis, male infertility, very salty-tasting skin (as the sweat glands cannot take up chloride ions, enabling excessive amounts of salt to escape in the sweat), bulky stools, persistent coughing, wheezing, pneumonia and fatigue.

The Diagnosis of CF

CF is usually diagnosed in infancy as a result of failure to thrive, persistent chest infections and/or persistent coughs. A definitive diagnosis is made through a Sweat Test, which measures the amount of salt in the sweat. In the future it is hoped that a mass screening programme will be implemented so that people can find out, prior to starting their families, whether they are at risk of having a child with CF. Whilst pre-natal testing is offered in families with members who already have CF, to date most families are only identified following the birth of an affected child, thus explaining the persistent, high prevalence rate of this disease.

The Treatment of CF

To date CF remains incurable and thus treatment primarily supports the physiological complications of the disease, aiming to relieve discomfort and to minimise and delay its effects. Despite advances, the treatment of CF remains complex and time-consuming. The precise treatment prescribed depends upon the stage of the disease and which organs are involved. The main treatments for CF include:

Antibiotic treatments

For the prevention and treatment of chest infections.

Pancreatic Enzyme Supplementation

To manage Pancreatic Insufficiency. Commercial preparations of pancreatic enzymes facilitate the absorption of nutrients from the intestinal tract. This aids the digestion of food, which in turn enhances nutrition and consequently weight gain and growth. An individualised approach to pancreatic enzyme replacement is required due to the variability in dietary intake, the residual capacity of the pancreas and pancreatic enzyme release and activation (Family Resource Centre, 1996). Dependent upon the amount of fat in the meal or snack about to be eaten, patients must take up to 15 enzyme capsules before and/ or during eating.

Further Prescribed Medications

Aerosol medications help to liquefy the mucus and sputum, while anti-wheezing medications and inhaled steroids decrease the amount of inflammation in the lung. Daily vitamin supplementation includes vitamins A, B, C, D and E. Vitamin K is prescribed for those with significant liver involvement.

Physiotherapy

Daily airway clearance regimens are prescribed to facilitate the respiratory management of CF by clearing mucus from the chest. Exercise is also encouraged to facilitate physiotherapy (Prasad et al., 2000).

Nutrition

Diet

Good nutrition is emphasised as a mainstay of therapy as good nutritional status is directly associated with health status (Dalzell et al., 1992). Indeed, improvements in nutritional status are associated with better growth (Hanning et al., 1993), and an improvement or stabilisation of pulmonary function (Levy, Durie, Pencharz & Corey, 1986). Conversely poor nutritional status and thus low weight are associated with a reduced life expectancy (Hanning et al., 1993). The malabsorption of nutrients (with consequent malnutrition), the recurrent pulmonary infections (with consequent increased exertion in breathing), as well as increased metabolic rates and the regular performance of physiotherapy are all thought to increase the energy requirements of those with CF above those of healthy peers (Hubbard, 1985). Thus it is recommended that, as well as taking pancreatic enzyme supplementation, CF patients consume 120-150% of the recommended daily allowance (RDA) of energy calculated for the weight and height of healthy individuals (MacDonald, 1996). It is also recommended that between 35-45% of energy intake is fat and sugar (MacDonald, 1996) as a high energy and fat diet is associated with better growth and survival (Corey, McLaughlin, Williams & Levison, 1988). Patients are thus prescribed a very nutritious diet with a high protein content and many calories. Many patients are also encouraged to drink high-calorie drinks to facilitate their nutritional status. The emphasis on good nutrition and satisfactory weight takes precedence over the other treatments offered throughout the life of the CF patient.

Enteral Feeding

When patients either fail to gain weight or lose weight whilst growing, or are consistently

less than 85% expected weight for height once they have stopped growing, for a period of between 3-6 months, enteral feeding is initiated (MacDonald, 1996). This usually occurs overnight through a nasogastric tube or via a gastrostomy, directly into the stomach. MacDonald (1996) found that the majority of those requiring enteral feeding were adolescents, which, she states, partly reflects the progressive nature of the disease and subsequent deterioration in nutritional status as patients get older, but may reflect psychological issues also, such as weight and shape concerns.

IN SUMMARY

CF is a progressive, genetic condition that primarily affects the respiratory and digestive systems. Growth and weight are compromised due to the impact of respiratory infections upon appetite and energy requirements, and the inadequate absorption of nutrients from the intestinal tract. There is no known cure and current treatment regimens aim to support the physiological complications of the disease. The main thrust of treatment focuses upon nutrition, as good nutrition has been associated with improved health status and longevity. If weight remains low enteral feeding is initiated but it is unclear to date whether low weight is a result of the condition alone or whether psychological issues play a part in its maintenance.

Eating Disorders, Atypical Eating Disorders and Eating Disturbance

Eating Disorders

Eating disorders such as Anorexia Nervosa (AN) and Bulimia Nervosa (BN) are characterised by severe disturbances in eating behaviour. They represent a significant public health concern (Killen et al., 1994), particularly amongst adolescents, which is

when they typically become evident (Fisher et al., 1995). Women between the ages of approximately 15 and 35 represent the majority of individuals who present with and receive treatment for eating disorders (Bryant-Waugh, 2000). The American Psychiatric Association (1994) estimate that the mean age of onset for AN is 17, with peaks at 14 and 19. BN is rarely seen in adolescents younger than 13 years of age (Bryant-Waugh, 2000). However this may actually reflect the small number of individuals who present for treatment at this age. Bryant-Waugh (2000) notes that bulimic adults often report that their eating difficulties commenced in early adolescence and thus it may be that adolescents do not seek treatment due to the shame and secrecy often associated with bingeing. Research suggests that eating disorders are becoming increasingly evident in the male population (Lask & Bryant-Waugh, 2000), in pre-pubertal adolescents (Lask & Bryant-Waugh, 2000) and in different ethnic and socio-economic groups (Lacey & Dolan, 1988). The incidence of AN and BN appears to have increased dramatically over the last 50 years (Polivy and Herman, 2002), although it is important to note that this may reflect a greater awareness of their existence in this population and hence greater reporting (Wakeling, 1996).

The Diagnosis of Eating Disorders

Bryant-Waugh (2000) notes that it is currently accepted that 'true' eating disorders can occur from approximately eight years of age upwards. She suggests that formal eating disorders are distinguishable from the relatively common feeding and weaning difficulties in infancy and the experience of food faddiness and selective eating patterns in pre-school children, as the former are not developmentally appropriate, whilst the latter two feeding difficulties are. She suggests that from eight years upwards, the child's

cognitive development is more sophisticated, rendering it more likely that eating difficulties are related to underlying psychological issues, such as self-evaluation, thus fitting the diagnostic criteria of DSM-IV (APA, 1994).

To date no formal diagnostic criteria exist that have been standardised for children and adolescents specifically (Bryant-Waugh, 2000). The two main systems that have been developed and standardised for the diagnosis of eating disorders in adulthood are the Diagnostic and Statistical Manual of the Mental Disorders (4th Edition) (DSM-IV) (American Psychiatric Association, (APA), 1994) and the International Classification of Mental and Behavioural Disorders-10 (ICD-10) (World Health Organisation, 1992; 1996). DSM-IV distinguishes between two sub-types of AN, the restricting type and the binge-purge type. This is not evident in the ICD-10 system. For this reason DSM-IV (APA, 1994) is utilised more commonly to date for the diagnoses of eating disorders in all ages, as it takes account of the variations commonly observed in clinical practice. The diagnostic criteria utilised by DSM-IV (APA, 1994) for AN and BN are listed in Appendices 1 and 2 respectively and will not therefore be described further.

The Prevalence of AN or BN in the Adolescent Population

The DSM-IV criteria (APA, 1994) have been utilised to date to provide prevalence estimates for AN and BN in the adolescent population. It is currently estimated that approximately 3-4% of the female, adolescent population meet the criteria for AN or BN, as defined in DSM-IV (APA, 1994). The prevalence of AN in female adolescents is approximately 1%, whilst the prevalence of BN ranges from 1-3% (Carr, 1999). Doyle and Bryant-Waugh (2000) document prevalence rates of between 0.5-1% for AN and 1%

for BN for this population. Eating disorders are also known to occur in adolescent males (Bryant-Waugh, 1994; Fichter & Daser, 1987) and in pre-pubertal adolescents of both genders (Fosson, Knibbs, Bryant-Waugh & Lask, 1987; Gowers, Crisp, Joughin & Bhat, 1991). Formal prevalence studies regarding males are not evident in the literature. However, Hawley (1985) found that 19% (n= 21) of his sample of participants with AN aged 13 or younger when diagnosed, were male, whilst Higgs, Goodyer and Birth (1989) found that male anorexics accounted for 30% of their adolescent sample (n=27). Carr (1999) estimates that the male: female ratio for eating disorders is approximately 1:9. This suggests a prevalence of approximately 0.08% in the adolescent, male population.

Lask and Bryant-Waugh (2000) estimate that the prevalence rates of AN and BN in pre-pubertal adolescents are lower than post-pubertal adolescents but again, formal prevalence rates are not evident in the literature. Whilst eating disorders remain more prevalent in Western, industrialised nations, they are now known to be evident in an increasing proportion of individuals from different ethnic and socio-economic groups (Lacey and Dolan, 1988). Whilst formal prevalence rates of eating disorders in different ethnic groups are not evident in the literature, several authors have documented their existence in clinical settings particularly within the Asian adolescent population (Bhadrinath, 1990; Bryant-Waugh & Lask, 1991).

The variation in the prevalence rates of eating disorders is likely to reflect both the type of data source and the number of data sources examined, both of which are likely to influence the overall reported prevalence of any disorder (Doyle & Bryant-Waugh, 2000). Hoek (1993) reviewed epidemiological studies of eating disorders and found that

approximately 370 cases of AN were evident in the community per 1,000,000 of the population annually. However only 30 cases of AN were evident in the same population if the source was psychiatric in-patients. Thus dramatic differences in prevalence rates can be seen dependent upon the type of population under investigation.

The diagnostic criteria within DSM-IV (APA, 1994) have developed and thus have altered over the past 30 years (Doyle & Bryant-Waugh, 2000). Consequently it may be that those who met diagnostic criteria 30 years ago would not do so currently, or vice versa. This renders it difficult to obtain a reliable prevalence rate of eating disorders. Further, the use of different diagnostic classification systems and differing methods utilised to detect cases render it difficult to interpret research across studies. It can therefore be concluded that the prevalence rates of eating disorders are likely to be estimates only and thus should be considered with caution. As Doyle and Bryant-Waugh (2000, p.57) note, "it would appear that all reported rates are an underestimation of the true rate of the disorders in question".

The Diagnosis and Prevalence of Atypical Eating Disorders and Eating Disturbance

Atypical Eating Disorders

Within the DSM-IV (APA, 1994), those disorders that do not meet the criteria for any specific eating disorder are known as 'Eating Disorder Not Otherwise Specified' (EDNOS). The diagnostic criteria for EDNOS can be seen in Appendix 3. They reflect atypical or 'partial' eating disorders. The prevalence rates described above represent formal diagnoses of AN or BN but exclude partial syndromes. Nicholls, Chater and Lask (2000) suggest that atypical eating disorders syndromes may account for up to 50% of

cases referred to clinical services. Research has found that atypical eating disorders are much more prevalent within this population than formal diagnoses, for example Thompson and Smolak (2001) note that an analysis of the prevalence data on AN and BN indicates that a significant percentage of adolescents with eating difficulties may meet the criteria for a partial syndrome. Indeed, Killen et al. (1994) found that 1% of their sample of 11-12 year-old females met the criteria for BN, whilst 4% met their standard for a partial syndrome.

Eating Disturbance

The prevalence rates described above also exclude eating disturbance, which incorporates less severe or sub-threshold levels of the criteria utilised within AN and BN, including restrictive eating practices, body image disturbance and appearance dissatisfaction. Symptoms of less severe eating disturbance appear to be particularly prevalent within the general adolescent population (Thompson & Smolak, 2001). Childress, Brewerton, Hodges and Jarrell (1993) surveyed eating disorder symptoms in 3,129 9-16 year-olds. They found that 40% wanted to lose weight and felt fat. Serdula et al. (1993) surveyed 6,000 male and female adolescents. They found that 16% and 47% of males and females respectively felt concerned about their weight. Field et al. (1999) found similar prevalence rates of weight dissatisfaction in 19% and 44% of 16,000 male and female adolescents. It is important to note that less severe difficulties within the general adolescent population may not necessarily require professional attention making it particularly difficult to provide clear estimates.

A Continuum between Eating Disturbance and Eating Disorders

Eating disturbance may not necessarily indicate the existence of a formal, clinical eating disorder, which might require treatment. However, evidence is emerging to suggest that individuals who elicit such disturbance may engage in extreme behaviours and may go on to develop a formal eating disorder diagnosis in later years (Thompson & Smolak, 2001). Indeed empirical evidence supports the notion of continuity between sub-threshold eating disturbances and full-syndrome eating disorders. Catterin and Thompson (1994) carried out a three-year prospective study of adolescent females. They followed participants from early to mid-adolescence (mean age at Time 2 was 15.3 years). Utilising regression analyses and controlling for the effects of age and weight status, they found that body dissatisfaction at Time 1 predicted the level of restrictive eating behaviours three years later. Stice, Killen, Hayward and Taylor (1998) carried out a four-year prospective study of 543 females (mean age of 14.9 years) and found that dieting behaviour predicted the onset of binge eating and purging four years later. It seems therefore that those who do not meet the full DSM-IV criteria (APA, 1994) require identification and possible clinical intervention consequent to the possible social, occupational or educational impairment experienced as a result of particular difficulties. As Nicholls et al. (2000, p.323) note, "Experience tells us that disorders not included in the classification systems are under-recognised, with potentially serious consequences".

Evidence suggests that eating disturbance may stem from eating difficulties in childhood. In their longitudinal study of eating disorders, Marchi and Cohen (1990) found that fussy eating and digestive difficulties such as constipation, diarrhea and abdominal pain in childhood were predictive factors in the aetiology of AN. They hypothesise therefore

that early experiences relating to food and bowel habits are associated with the development of eating disorders in later years. This supports the notion of an eating disorders developmental continuum.

The Prognosis of AN and BN

Despite an increased awareness of eating disorders, our current understanding of factors that influence their development remains limited (Fairburn and Beglin, 1990). This is reflected in the modest outcomes obtained from current treatment programmes to date (Kreipe and Uphoff, 1992). Yager et al. (1993) utilised the currently recommended multi-disciplinary, family-focused treatment programme. They found that only 44% of patients followed up for approximately four years post onset obtained a 'good' outcome, which they described as reaching at least 15% of their ideal weight. Many of the features that characterise AN in particular have been found to normalise once weight gain has commenced in individuals who reached puberty and stopped growing prior to the onset of symptoms. However, in adolescents who are still growing and have not reached puberty, many of these 'reversible' characteristics have been found to persist. Persistent difficulties can be seen in Table 1-1.

Table 1-1: The Persistent difficulties associated with developing an eating disorder in early adolescence

Pre-pubertal Adolescents

Incomplete Pubertal Development:

Results in a lack of oestrogen or testosterone, which has adverse effects upon the development of:

Healthy bones

Secondary sexual characteristics

Reproductive function

These may be irreversible

Growth:

Variable catch-up growth.

Growth arrest is common

Lambert and Cattani-Thompson (1996) suggest that the identification of eating disturbance before it develops into a formal eating disorder is likely to improve the prognosis, as difficulties are less severe and the illness is shorter in duration and consequently less entrenched.

Mortality rates relating to the physical complications of eating disorders (such as malnutrition and electrolyte imbalance), and also to suicide (Crisp et al., 1992) appear to have reduced over the past decade to less than five percent. Nevertheless AN and BN continue to have the highest mortality rates of any category of psychiatric illness (Hoffman & Halmi, 1993; Herzog & Bradburn, 1992). The modest treatment outcomes and evidence of mortality rates in the eating disorder population suggest that eating disorders remain serious and potentially life-threatening conditions.

IN SUMMARY:

A significant proportion of adolescents appear to have either formal eating disorders or experience eating disturbance. The latter group may be at risk of developing a formal diagnosis in the future. The evident relationship between the two as well as the physical complications associated with developing a formal eating disorder, coupled with the evidence of mortality in the eating disorders population and modest treatment outcomes, suggests that eating disorders remain of serious concern. The identification and treatment of eating disturbance before it has the chance to develop into a formal eating disorder therefore appears vital.

Risk Factors Associated With The Development Of Eating Disorders

It is currently hypothesised that the same risk factors apply to both AN and BN but that personality traits may play a role in the development of one as opposed to the other. For example, Bryant-Waugh (2000) hypothesises that perfectionistic personality traits may be an important factor in maintaining the necessary restraint needed to ensure low weight in AN patients. In BN, common personality traits observed include gregariousness, impulsivity and risk-taking, all of which are incompatible with the need to exercise control observed in AN. Rather such traits appear to encourage binge/purge behaviours (Roberts, 1995).

In order to examine why adolescents with CF might be at an increased risk of developing eating disorders or eating disturbance, the most commonly cited risk factors that have been examined to date in the general adolescent population are described below. Genetic factors, biological and specific environmental factors such as the role of the family and peers have been excluded as, whilst their importance is acknowledged, they are not pertinent to this research project.

Adolescence and Puberty

Developmental factors specific to adolescence have been associated with the onset of AN in particular. Puberty has been documented as a significant temporal indicator and evident catalyst for eating disorders in adolescence (Sands, Tricker, Sherman, Armatas & Maschette, 1996). For females puberty is associated with a significant increase in adipose tissue, which results in an increase in body fat (Striegel-Moore et al, 2000). Striegel-Moore et al. (2000) suggest that it is this increase that contributes to the increase in body

dissatisfaction and other symptoms associated with eating disorders such as drive for thinness. They utilised the Eating Attitudes Test (EAT-26) (Garner, Olmsted & Polivy, 1982) to examine eating disorder symptomatology in 1,902 11-16 year-old females. The EAT-26 is a self-report checklist, consisting of 40 questions presented in a six-point forced choice Likert scale format. It measures the presence and severity of the eating problems that are common features of AN, namely a preoccupation with food, binge/purge behaviour and resistance to eating. They found a positive association of age with weight concerns and dieting, and a direct association between Body Mass Index (BMI), body dissatisfaction and drive for thinness, which they attributed primarily to the developmental changes associated with puberty, specifically weight gain. Striegel-Moore et al. (2000) suggest the onset of puberty thus focuses the individual upon their body shape and weight.

The process of individuation commonly cited in developmental theories such as Erikson's Psychosocial Theory of Development (Erikson, 1968) renders personal control an important issue during adolescence, which may act to trigger weight control behaviours in vulnerable adolescents. The formation of social bonds during adolescence is also likely to render this age group particularly sensitive to others' evaluation of their appearance, specifically as there appears to be a developmental shift with the views of parents becoming less important and the views of peers becoming more important as a function of age (Harter, 1989; 1990). Woodl, Waller, Miller and Slade (1992) note that the normative level of unhealthy attitudes to eating increases during adolescence, which may be associated with the emergence of formal eating disorders during this developmental phase. However, to date it remains unclear why a minority of adolescents

develop formal eating disorder psychopathology, whilst other adolescents do not. Clearly other variables require consideration.

Body Dissatisfaction

Studies indicate that children as young as six years of age express body dissatisfaction and thus weight concerns (Davison, Markey & Birch, 2000; Flannery-Schroeder & Chrisler, 1997), which appear to increase with age (Tiggemann & Wilson-Barrett, 1997). Mellin, Irwin and Scully (1992) found that 30% of 9-year-olds, 55% of 10-year-olds and 65% of 11-year-old females worried about being too fat. This was also evident in a study by Thelen, Powell, Lawrence and Kuhnert (1992) who found that girls were more concerned about being over-weight and expressed stronger desires to be thinner as they got older. Shapiro, Newcomb and Loeb (1997) found comparable rates of dissatisfaction amongst older adolescent and adult females, which suggests that some components of disturbed eating are likely to be internalised at a young age. Hill and Bhatti (1995) found that Asian girls as young as nine years of age were dieting and rated thinness as a high priority.

Studies examining male body dissatisfaction are limited and have elicited contradictory results (Smolak & Levine, 2001). Hill, Draper and Stack (1994) and Hill and Pallin (1998) did not find gender differences in overall body dissatisfaction, whilst Field et al., (1999) and Tiggeman and Wilson-Barrett (1998) found that boys were generally less dissatisfied and had fewer concerns about their body shape and weight than females. The clinical findings of Bryant-Waugh (2000) suggest that boys are more concerned with preventing the development of a flabby shape than wanting to lose weight, thus, whilst

their motive for particular behaviours differs from females, the same results are obtained in terms of weight loss and symptomatology.

Many researchers have noted significant gender differences but have failed to distinguish whether their participants were dissatisfied that they were too light and too thin or too heavy and too fat (Smolak & Levine, 2001). Wood, Becker and Thompson (1996) found that virtually all of the body-dissatisfied females in their study wanted to be thinner whereas only approximately half of the boys did. This suggests that some of the body-dissatisfied boys may have wanted to be heavier. Some dissatisfaction in male adolescents may therefore be a result of being too thin. It is difficult to draw definitive conclusions about body dissatisfaction in the male, adolescent population, but evidence of formal eating disorders suggests that any concerns require identification and thus further research is required.

Dieting

Evidence suggests that body dissatisfaction predicts eating behaviour, for example, Halvarsson, Lunner, Westerberg, Anteson and Sjoeden (2002) found that an increased desire to be thinner led to significant increases in dieting behaviour amongst 1,076 females aged between 7 and 15 years. Hsu (1990) believes that dieting in adolescence due to body dissatisfaction can trigger the onset of an eating disorder due to poor self-esteem, poor body image and poor identity formation. Patton, Johnson-Sabine, Wood, Mann and Wakeling (1990) propose that adolescent dieters are eight times more likely to develop an eating disorder than their non-dieting peers. Field et al. (1999) found that 19% and 44% of male and female adolescents respectively were actively dieting to lose

19% and 44% of male and female adolescents respectively were actively dieting to lose weight. However, the clinical findings of Bryant-Waugh (2000) suggest that boys also restrict their intake of fattening or unhealthy foods. This suggests that body dissatisfaction and weight loss behaviours such as dieting are common amongst both male and female adolescents.

Exercise

Coupled with dieting, exercise is another strategy for modifying body shape (Silberstein, Streigel-Moore, Timko & Rodin, 1988). Whilst dieting has been suggested as a significant risk factor in the development and maintenance of eating disorders, exercise has received little attention. Andersen (1999), Parks and Read (1997) and Sundogt-Borgen and Skarderud (1999) suggest that exercise is associated with eating disorders but this association appears to depend upon the reasons behind exercising. McDonald and Thompson (1992) found that exercising for reasons related to weight control and body tone were associated with elevated levels of eating disturbance in males and females. Field et al. (1999) found that intense exercising was utilised more than dieting in both male and female adolescents.

Self-Esteem

Coleman and Hendry (2000) consider self-esteem to refer to the individual's self-evaluation or sense of self-worth. Research has consistently found that satisfaction with one's physical appearance, including one's body-image is one of the main contributing factors towards one's global self-esteem (Harter, 1990). Indeed, Blyth, Simmons and Zakin (1985) found more favourable body-image and self-esteem in adolescents who

approximate the cultural ideal of thinness. Low self-esteem has therefore emerged as a further risk factor in the development of eating disorders (Button, 1990). Neumark-Sztainer, Butler and Palti (1996) found that low self-esteem was one of the strongest predictors of disordered eating when they tested a risk factor model utilising structural analyses to predict eating disturbance amongst 341 adolescent females. In a study examining 286 13-16-year-old females, Fryer, Waller and Kroese (1997) found that increased stress and maladaptive coping, both of which were directly associated with disturbances in eating attitudes resulted in low self-esteem.

Thomas, James and Bachmann (2002) found that low self-esteem was independently associated with a high score on the EAT-26 (Garner et al., 1982). They suggest that low self-esteem may mediate between other stressors towards the development of an eating disorder. Smolak and Levine (2001) suggest that physical appearance and body satisfaction are just as important to adolescent male self-esteem. However, Gardner, Sorter and Friedman (1997) suggest that adolescent males view puberty and their experience of the growth spurt more positively than females, thus experiencing less of an impact upon their self-esteem as a result. The limited research in this area renders it difficult to draw any firm conclusions and again further research is required. However it seems that self-esteem is closely associated to boy image and body satisfaction, rendering it of importance in the development of eating disorders.

Socio-Cultural Factors

Roberts (1995) notes how Western society appears to have embraced the notion of slimness as the ideal for females (Cash, Winstead & Janda, 1986) and the classic 'V'-

shape, tall and muscular physique for males (Pope, Olivardia, Gruber & Borowiecki, 1999). Killen et al. (1994) suggest that the cultural preoccupation and thus pressure on women to be thin is an important predisposing factor towards the development of eating disorders, as it may promote the expression of eating disorder symptomatology in vulnerable adolescents. The fact that eating disorders are not found in societies where fatness is valued yet are mainly confined to societies where thinness is valued helps to validate the view that cultural/societal beliefs and values are likely to contribute towards the aetiology of eating disorders. This view is supported by the finding that immigrants to Western societies do not develop eating disorders themselves yet their children appear to be just as vulnerable to developing an eating disorder than those indigenous to Western society (Bryant-Waugh & Lask, 1991).

The cultural emphasis on thinness and dieting appears to commence at an early age. Maloney, McGuire, Daniels and Specker (1989) surveyed 318 children aged between seven and ten years and found that 80% of 10-year-olds wanted to be thinner and 60% had already been on at least one diet. The percentage of those who reported having been on a diet doubled between the ages of seven and ten years. This suggests that attitudes and behaviours about body shape and weight are evident prior to puberty, rendering pre-pubertal adolescents of interest also.

Stressors

It is also important to note that specific stressors may also act to trigger the onset of an eating disorder. Gowers, North, Byram and Weaver (1996) note that profound life events such as the experience of illness or a bereavement can act to trigger the onset of

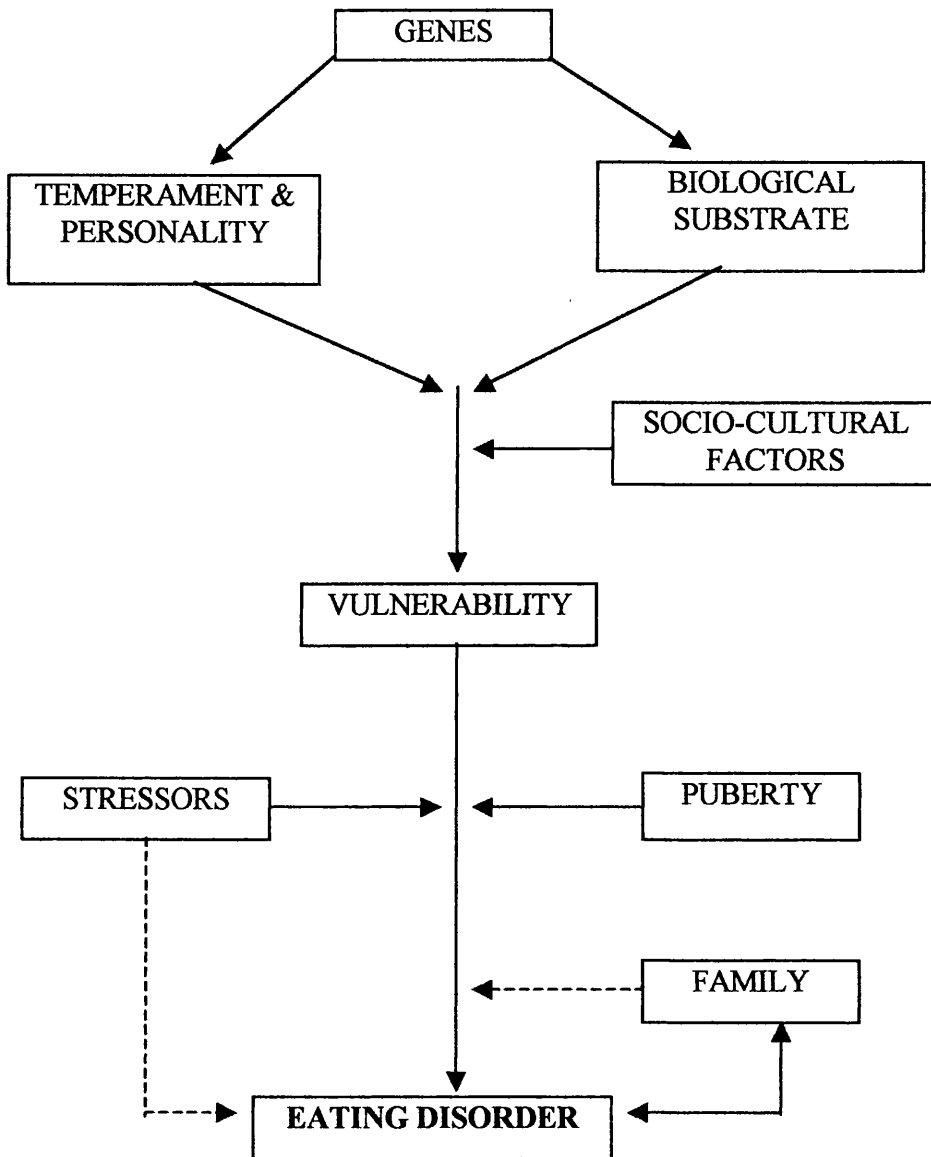
eating disorders. Schmidt, Tiller and Treasure (1993) hypothesise that life events may lead to identity insecurity thus increasing the risk of dieting and consequently eating problems, as such individuals may look to media role models, who provide inconsistent and unrealistic expectations, to define themselves. Watkins, Sutton and Lask (2001) investigated the correlation between the early onset of eating disorders and a history of physical illness in 28 7-19 year-olds. They found that those with AN were significantly more likely to have experienced a serious physical illness. They concluded that a history of physical illness is a significant risk factor for early onset eating disorders in general and for AN in particular when more than one physical illness has been present. Lask and Bryant-Waugh (1992) note the importance of considering that some of the factors described may be secondary to malnutrition and other components of the disease rather than aetiological factors.

IN SUMMARY:

It can be seen that difficulties associated with eating do not appear to have a definitive aetiology. Each risk factor plays a role in the development of such difficulties but appears to be neither necessary nor sufficient when considered in isolation. Eating disorders and eating disturbance therefore appear to have multi-factorial and multi-dimensional causes and thus, to gain a thorough understanding, a variety of risk factors must be considered (Garner, 1993; Hsu, 1990). A diagrammatic presentation of risk factors currently acknowledged to play a role in the development of an eating disorder can be seen in Model 1-1 (Lask, 2000).

Model 1-1: A Multi-Dimensional Model of the Development of an Eating Disorder

(Lask, 2000)



Why Might Adolescents With CF Be At Risk Of Developing Eating Disorders/ Eating Disturbance?

Eating Difficulties are evident from childhood in the CF population

The research described above points to a continuum from eating difficulties in childhood to the emergence of eating disturbance and formal eating disorders in later years. Studies that have explored feeding problems in young children with CF have consistently shown that mealtimes are difficult for children with CF and their parents, which suggests that this group may be particularly at risk of developing problems in later years (Sanders, Turner, Wall, Waugh & Tully, 1997; Singer, Nofer, Benson-Szekely & Brooks, 1991; Stein & Fairburn, 1994).

The requirement of a high daily calorie intake of between 120-150% of the RDA of energy calculated for the weight and height of healthy individuals (MacDonald, 1996) can prove difficult for a sick child, with a poor appetite, who might respond by either coughing, gagging, spitting food out or refusing food altogether (Christ et al. 1994; Jelalian et al., 1995). These difficulties may be exacerbated by anxious parents, who acknowledge the importance of a high calorific diet to their child's health, and thus may respond by engaging in inappropriate or aversive behaviours, such as spoon-feeding the child at the table or providing vague commands or a repeated string of commands, which leave very little opportunity for cooperation (Christ et al., 1994; Jelalian et al., 1995). Stark et al. (1996) suggest that such difficulties are exacerbated by doctors and health visitors who emphasise weight gain within treatment. Singer et al. (1991) suggest that such behaviours can lead to a vicious cycle of mealtime problems leading to parental

anxiety, which increases tension and consequently increases disruptive behaviour. This suggestion is validated by findings of continuing eating problems in school-age children with CF (Tomezsko et al., 1992; Stark et al. 1997). Both studies found that children aged between 5-10 years were not consuming their full, recommended daily allowance for energy and were behaving in a similar manner to younger children at meal times. Stark et al. (1997) note that their sample had significantly low heights and weights for their ages, which validates both parental and clinical concerns about eating in this population. Very few studies have reported eating difficulties in adolescents with CF. They will be reviewed in the section on 'Adolescence' below. However it is suggested that such difficulties are evident then also (Pearson, Pumariega & Seilheimer, 1991).

Adolescents with CF experience low self-esteem

Whilst adolescents with CF generally experience delayed puberty, once it has started it generally progresses in the normal pattern, which means that adolescents with CF are exposed to similar physical changes as their non-CF peers (Weltman et al., 1990). Adolescents with CF have been observed to experience low self-esteem (Sinnema, Bonarius & Van der Lang, 1988; Pearson et al., 1991; Sawyer, Rosier, Phelan & Bowes, 1995), which has been associated with poor body image as a result of delayed growth and delayed puberty (Sinnema et al., 1988; Sawyer et al., 1995). Strauss and Wellisch (1980) found that concerns regarding physical appearance, such as short stature and a delayed development of secondary sexual characteristics were the most distressing symptoms other than the chronic cough experienced by adolescents. The association between self-esteem and satisfaction with one's physical appearance within the CF population is consistent with findings within the general population. The nature of eating

disorders/ eating disturbance suggests dissatisfaction with one's physical appearance. This suggests that, within the CF population, those with an eating disorder/ eating disturbance are likely to have lower self-esteem than those without.

For the adolescent with CF, the difference in physical appearance may also impact upon social acceptance by peers (Esmond, 2000). This could be influenced further by the increase in hospital admissions as the disease progresses, which results in time away from school and potential difficulties with friendships as a result. Increased hospital admissions mean that the CF adolescent often has to catch up on academic work, which may compromise academic achievement. Due to the lung disease, they often find exercise difficult and, as the illness progresses, they are often unable to participate in sport rendering sporting success unlikely. Currently the United Kingdom adheres to a segregation policy to prevent patients with CF from spreading bacterial lung infections between each other (The CF Trust, 2000). This means that CF patients are prevented from mixing with each other. Schools try to ensure that they only have one CF patient within the school. The implications of this policy have not been formally researched to date. However it is hypothesised that this policy may impact upon self-esteem, particularly in adolescence when individuals cannot discuss their experiences with peers in the same predicament, which could exacerbate current feelings of difference.

Adolescents with CF are likely to experience a number of Stressors

Adolescents with CF are likely to experience a significant number of life events, which could be construed as stressors. There is a high likelihood of exposure to losses such as deaths of siblings and friends (prior to the implementation of the segregation policy

(Goldbloom, 1988), coping with increased hospital admissions and more aggressive treatments as the disease progresses as well as considering one's own mortality at a time when peers are considering their future. A fundamental reality for all CF patients is the existence of a chronic and incurable disease, the presence and development of which is completely outside their control. A common way to cope with this issue may be to attempt to control other aspects of their lives such as eating, which is so strongly emphasised in treatment (Pearson et al., 1991). Goldbloom (1988) suggests that the experience of loss as well as a preoccupation with food may cause a vulnerability to eating disorders in this population. It has been noted in the diabetes literature that adolescent diabetics may express stress and conflict through non-compliance with dietary and medication regimes. "Such behaviours in the context of CF may lead to weight loss, a paradoxical valuing of thinness, and the setting into motion of the well described factors that may perpetuate anorexic behaviour" (Goldbloom, 1988, p.436).

Adolescents with CF are likely to subscribe to the same cultural values as their non-CF peers

Very little research has examined the impact of the Westernised cultural drive for thinness on the eating behaviour and body image of adolescents with CF. Jelalian et al. (1995) have examined body satisfaction in 30 8-15 year olds. They found dissatisfaction in both males and females. The males were dissatisfied because they wanted to weigh on average 7.9lbs more than their current weight whilst the females were dissatisfied as they wanted to weigh on average 1.2lbs less than their current weight. Consistent with these findings, they found that males were consuming a mean of 2, 885 calories per day in comparison to 2,031 calories per day consumed by females. There was a significant

positive correlation between the desire to weigh more and calorie consumption. These results fit the cultural gender ideals described previously and help to confirm the suggestion made by Sawyer et al. (1995) that adolescents with CF do not appear to be protected by society's current 'beauty myth' (Wolf, 1990), which equates being attractive with being thin if you are female and muscular if you are male. Adolescents with CF therefore appear to subscribe to the same cultural pressures that impact non-clinical adolescents. The drive for thinness, which is so common in Western civilisations (Roberts, 1995), is an easily attainable goal for adolescents with CF, and one that they appear likely to desire. It may be that under-nutrition, which is a common clinical observation in adolescents with CF may trigger the onset of or facilitate the emergence of an eating disorder.

CF may be a risk factor in itself

The very nature of CF may render certain individuals vulnerable to developing eating disorders or eating disturbance. The nutritional interventions offered include high calorie diets, supplements, naso-gastric tubes or gastrostomies, any of which may inadvertently create a situation of high stress and pressure around eating. Further, one of the fundamental characteristics of patients with eating disorders or eating disturbance is a preoccupation with food, exercise and weight, all of which are emphasised throughout the lives of CF patients. Goldbloom (1988) suggests that any condition that focuses attention on issues of food, weight and control may leave certain individuals at risk. Despite advances in medical treatment approximately 35% of people with CF maintain their height and/or weight below the 10th percentile, which meets Criterion A for AN (Stark et al., 1997). Whilst this may be solely a result of the physical implications of the

disease, adequate enzyme supplementation and a high calorie diet are sufficient to maintain an adequate weight (Pumariega, Pursell, Spock & Jones, 1986) rendering it unclear whether or not other psychological issues play a significant role in the maintenance of low weight.

IN SUMMARY:

Adolescents with CF experience many of the risk factors associated with the development of eating disorders and eating disturbance in the general adolescent population. They appear to adhere to the same cultural value of thinness as their non-CF peers, which is an easily attainable goal for them. Throughout their lives a preoccupation with food, shape and weight are encouraged, which may act to trigger eating disorder symptomatology in vulnerable CF adolescents. Evidence of low weight in this population, despite adequate treatments to reduce its likelihood, render it likely that psychological issues play a role in the maintenance of low weight in vulnerable adolescents with CF.

Evidence Of Eating Disturbance in Adolescents With CF

There has been very little research examining either eating disturbance or formal eating disorders in the adolescent CF population, which is likely to reflect the fact that it is only in recent years that CF patients have survived into adolescence and adulthood (Sawyer, et al., 1995). No studies appear to have directly examined eating disturbance. However several studies reveal concerning attitudes in adolescents with CF regarding their weight. Bell, Durie and Forstner (1984) found that 24 females aged between 10 and 17 years were consuming approximately 98% of their recommended daily allowance (RDA) of

the energy calculated for the weight and height of healthy individuals and 38.6% calories from fat. Whilst similar behaviour may be normal within the general adolescent population, the RDA is evidently far less than the RDA of between 120-150%, which is currently recommended for CF patients. Further, 38.6% calories from fat is at the lower end of the recommended 35-45% (MacDonald, 1996). These statistics suggest an insufficient consumption of energy to either maintain or gain weight.

Bearing in mind that Stark et al. (1997) found that approximately 35% of people with CF maintain their height and/or weight below the 10th percentile, which meets criterion A for AN, it is likely that a significant proportion of Bell et al.'s (1984) sample would have been under-weight, rendering their findings of considerable concern and reflecting a significant likelihood of disturbed eating attitudes and possibly disturbed eating behaviours in this sample. Similar concerns can thus be made regarding the findings of Jelalian et al. (1995), which were reported earlier. Unfortunately they do not provide either the specific ages or the size of their sample making it impossible to evaluate their findings more thoroughly.

Evidence of Formal Eating Disorders in Adolescents With CF

Studies that have examined the existence of formal eating disorders in the adolescent CF population have produced varied results and point to an atypical eating disorder presentation. Those that are evident in the literature will be described below.

Pumariega et al. (1986) identified 13 adolescents (10 female and 3 male) aged between 12 and 21 years, with CF and an atypical eating disorder similar to anorexia nervosa,

over a three-year period, through attendance at a CF out-patient clinic. This represents 12% of patients within that age range that attended the clinic. All 13 adolescents presented with significant weight loss of between 7-58% of their total body weight. Weight loss had occurred over a period of between four months and three years. They were all more than 25% below their ideal body weight and had lost weight despite either satisfactory pancreatic function or enzyme supplementation. Most patients had experienced a genuine loss of appetite subsequent to a pulmonary infection and consequent weight loss due to a reduced diet. However, they subsequently prevented weight gain, increasingly avoided thinking about food and denied their hunger and thus their weight loss continued after recovery from the infection. Further, amenorrhea and the obliteration of secondary sexual characteristics were evident in the females as was muscle wasting and fine, downy hair known as lanugo hair. The sample did not demonstrate a totally distorted body image or bingeing behaviours. However all denied their emaciation to a degree. Body image disturbance is a defining feature of AN. All developed dietary peculiarities and there was an increase in 'control struggles' over eating, which were exacerbated by parental concerns about their refusal to eat. Half the sample over-exerted themselves initially, despite poor caloric intake. Vomiting, bingeing or other purging behaviours were not identified within the sample.

It is assumed from the above study that the authors utilised DSM-111 criteria (APA, 1980) for diagnosing atypical eating disorders although this is not made explicit. Although their findings are of significant relevance to the field, they appear to be a result of clinical observation and thus the study does not appear to have adhered to strict scientific methodology, for example utilising two blind, independent raters to assess for

inter-rater reliability regarding diagnosis.

Pearson, Pumariega, Seilheimer and Bartholomew (1988) examined adjustment in CF patients. They reported that 11 patients with CF (18%) aged between 8 and 15 and one patient (2%) aged between 16 and 40 had scores greater than or equal to 26 on the EAT-26 (Garner et al., 1982). Unfortunately they provide no further evaluation and thus it is unclear exactly how many of their sample had a diagnosed eating disorder, as the measure cannot provide a formal diagnosis. Further, they utilised a self-report measure, which is advantageous in providing respondents' direct views, but may result in under-reporting of symptomatology as it elicit views that are likely to be highly subjective and may not fit with reality. The tool was originally validated for females only and its validity in this sample remains unclear.

In their clinic sample of 50 10-20 year-olds, Steiner, Rahimzadeh and Lewiston (1990) interviewed patients whose weight was less than or equal to 75% ideal body weight (as determined by the National Health Examinations Survey, 3rd cycle, 1966-1970) or those who were less than 18 years of age who had failed to make expected weight gain during the growth spurt, leading to body weight 15% below that expected. 10 out of 11 CF patients met these criteria and agreed to participate. The participants were matched with 10 participants from an eating disorders program for sex, SES, age, menstrual status, body morphometry, body mass index and pubertal development. All participants underwent a one-hour psychiatric exam by two independent raters, resulting in a DSM-111R diagnosis (APA, 1987). Inter-rater reliability was 80%. They did not identify formal eating disorders in their CF sample. However they utilised diagnostic criteria alone, ignoring any patterns of eating disturbance within their sample.

Pearson et al. (1991) interviewed 61 8-15 year-olds with CF also utilising the EAT-26 (Garner et al., 1982). They found that 16.4% of their sample reported symptoms consistent with anorexia nervosa in comparison to a prevalence rate of 0.0001-1% of anorexia nervosa in the general population at that time (DSM-111-R) (APA, 1987). They conclude, "Since nutritional management is so strongly emphasised in the care of the CF patient, eating may well serve as a convenient mechanism for this age group to express underlying conflicts" (Pearson et al., 1991, p.295). Again the results of this study are based upon data from self-report measures, the results of which cannot be extrapolated to formal Eating Disorder diagnoses. Further, they state "the majority of the current sample was male" (Pearson et al., 1991, p.291), and thus they eliminated the question asking about menstruation and prorated the cut-off score to 27+, which they state, "is similar to the procedure used by Zellner, Harner & Adler (1989)". It is not documented whether this has been validated for use with males. The study does not provide the reader with a clear understanding of their sample, making this study difficult to replicate. The authors do state that the traditional measures utilised in this study may not detect eating problems in this particular population, rendering eating disorders or eating disturbance potentially under-reported phenomena in this population.

Pumariega, Pearson, and Seilheimer (1993) examined adjustment in 44 7-15-year olds with CF. They also utilised the EAT-26 (Garner et al., 1982). They found that 15.6% (n=7) scored above the cut-off, and that this was not correlated with illness severity. Unfortunately the authors fail to provide details of eating disorder symptoms. However, they still found a significant proportion of symptoms in a small sample size, which suggests that eating disturbance is likely to be prevalent in this population.

Raymond et al. (2000) examined rates of eating disorders and psychopathology in 58 patients with CF, aged between 13 and 20 years, and 43 healthy controls. They utilised the National Institute of Mental Health Diagnostic Interview Schedule (DIS) (Robins, Helzer, Cottler & Goldring, 1989), the Eating Disorders Questionnaire (EDQ) (Mitchell, Hatsukami, Eckert & Pyle, 1985) and the Eating Disorders Inventory (EDI) (Garner & Garfinkel, 1989). They diagnosed eating disorders in two of the control participants but none of the CF participants but concluded that CF patients do have eating behaviour problems. However they failed to describe these particular findings in detail. Once again, self-report measures were utilised and the validity of the DIS with this population was not evaluated.

Summary of research findings to date

Out of the above six studies, four reported eating disorder symptomatology. Of those four, two reported elevated EAT-26 scores, which reflects the presence of the eating problems consistent with features of AN, namely a preoccupation with food and resistance to eating. Two studies reported anorectic symptomatology, including weight loss and avoidance of weight gain. None of the studies found evidence of binge-eating or purging behaviours in their samples. These findings suggest that patients with CF and an eating disorder/eating disturbance are more likely to experience symptoms related to AN than symptoms related to BN.

The four studies that found evidence of eating disorder symptomatology reported such symptoms in participants between the ages of seven and 40 years of age. CF is a progressive illness and consequently symptoms associated with eating disorders/ eating

disturbance are likely to have been evident irrespective of the severity of the CF itself, as younger CF patients are likely to have less severe CF than older CF patients. However it is important to note that prolonged eating disorder/eating disturbance symptomatology would effect health status over time.

Summary of the Limitations of research to date

Despite these findings, it is difficult to make any firm conclusions as four studies utilised self-report measures, resulting in a subjective measurement of such difficulties. They did not utilise formal clinical assessments to validate findings, thus making it difficult to assess the extent and degree of the problem. The other two studies utilised clinical interviews, which do not take account of the exact nature of eating disorder symptomatology in this population. Further, the studies all utilised different sample sizes (where documented) and varying age groups, ranging from 7-40 years. None of the studies explicitly document the age or gender of those where eating difficulties were evident.

IN SUMMARY:

The limited number of research studies that have examined eating disorder symptomatology in the adolescent CF population reveal that eating disorders and/or eating disturbance are evident in this population. Those that have found evidence of eating disorder symptomatology demonstrate anorectic symptoms, although there is no evidence to support a distorted body image. Different sample sizes, age groups and the use of self-report measures or clinical diagnostic criteria alone and a failure to examine particular patterns of symptomatology make it difficult to reach any firm conclusions.

Comorbidity: Distinguishing Eating Disorder symptomatology from CF

Steiner et al. (1990) (as described in detail above) note that chronic malnutrition (often experienced by CF patients) can produce psychopathology and eating behaviours similar to those found in AN. Their study aimed to identify features unique to AN versus those that are secondary to malnutrition and delayed pubertal onset. Whilst they did not find evidence of formal eating disorder symptomatology, their results revealed significant differences between their CF group and their group with AN. In particular the AN group showed more psychopathology and their families showed fewer adaptive coping strategies than the CF group. Further, core features of AN (including drive for thinness, body dissatisfaction, ineffectiveness, lack of interoceptive awareness and disordered eating behaviour), differentiated these two groups equally affected by malnutrition and pubertal delay.

The findings of Steiner et al. (1990) support their hypothesis that malnutrition and an altered body composition do not result unconditionally in the psychopathology associated with AN. This validates AN as an entity distinct from other pathological nutritional states and suggests that features of mood disturbance and ego deficits within the AN group are independent of body composition, nutritional and maturational status.

The overlap of some of the key symptoms of eating disorders with the symptoms of CF renders the diagnosis of an eating disorder potentially difficult in this population (Powers, 1997). However, the results of the study by Steiner et al. (1990) highlight the importance of identifying and treating the psychopathology related to eating disorders where appropriate, rather than assuming that any problems are secondary to CF alone.

IN SUMMARY:

The core features of AN including drive for thinness, body dissatisfaction and disordered eating behaviour differentiate AN patients from CF patients, revealing that the features of AN are a distinct entity and are not secondary to malnutrition alone. Such features are therefore distinct from conditions like CF, which are also influenced by malnutrition and pubertal delay. The similarities yet distinct differences between CF and AN underlines the importance of ensuring that eating disorders do not go unnoticed in the CF population purely because it is common for adolescents with CF to be under weight.

A Need For Further Research

Research into eating disorders and eating disturbance is in its infancy relative to research into other psychiatric conditions (Neiderman, 2000) and this is particularly evident regarding different populations who may be at particular risk of developing such problems, one of which is the adolescent CF population. It is important to clarify whether or not the adolescent CF population is at an increased risk of developing eating disorders, utilising methodology that clarifies the exact nature of any possible eating difficulties. This can be considered in clinical practice and treated accordingly, particularly as low weight in this population is directly associated with reduced life expectancy (Bell et al., 1984). As Goldbloom (1988) notes, the medical and nutritional care provided for individuals with CF may be severely misdirected by being unaware of a coexisting eating disorder or of an eating disturbance in particular individuals.

Continuing research into eating disorders will ensure that a more thorough account of their course is obtained, which will improve treatments, outcomes and ultimately quality

of life for patients of differing populations including the adolescent CF population.

The methodological limitations of previous research studies preclude firm conclusions regarding the nature and prevalence of formal eating disorders and eating disturbance in the adolescent CF population. However, despite their limitations they do suggest a vulnerability towards eating disorders in female and male adolescents with CF. Although eating disorders and eating disturbance are serious in any population, they are potentially fatal in those with CF, due to the detrimental impact that low weight has upon respiratory function and health status (MacDonald, 1996). A more thorough understanding of the association between eating disorders and CF is consequently vital.

THIS STUDY

Although previous studies have found relatively low prevalence rates of eating disorders, it may be that this reflects the use of tools that do not reliably identify difficulties in this particular health population. Further, clinicians who work with CF adolescents believe that eating disturbance and eating disorders are prevalent, which does not fit with the research findings to date. This study therefore aims to improve on previous research designs, by utilising a semi-structured, interview-based tool, which has been designed to identify and to describe formal eating disorders and eating disturbance in children and adolescents and is therefore deemed to be a more reliable tool. The study will also compare findings from two different CF centres, thus facilitating the generalisation of results within this population.

Research Questions and Hypotheses

Qu. 1) What are the nature and prevalence of a) formal eating disorders and b) eating disturbance in adolescents with Cystic Fibrosis?

Hypothesis 1) Adolescents with a) eating disorders and b) eating disturbance are more likely to experience symptoms related to Anorexia Nervosa such as restraint from eating than symptoms related to Bulimia Nervosa such as bulimic episodes.

Qu 2) How does the prevalence of a) eating disorders and b) eating disturbance in this sample compare to the general adolescent population and the diabetic adolescent population?

Qu 3) How do a group of adolescents with CF and a) eating disorders and b) eating disturbance compare with a matched group from the same population with CF but without eating disorders or eating disturbance on a range of variables including demographic variables, self-esteem and variables related to eating?

Hypothesis 2) a) Eating disorders and b) eating disturbance will be evident in adolescents with CF irrespective of the severity of their condition.

Hypothesis 3) The presence or absence of symptoms associated with a) eating disorders and b) eating disturbance will be related to differences in gender.

Hypothesis 4) The presence or absence of symptoms associated with a) eating disorders and b) eating disturbance will be related to differences in self-esteem.

CHAPTER 2

METHOD

Overview

Fifty-five participants were recruited from two different hospitals that specialise in the assessment and treatment of Cystic Fibrosis (CF). All participants completed a self-esteem questionnaire, and a semi-structured interview to assess eating disorder symptomatology. Demographic and clinical information were collected from the medical notes of participants and of those who did not wish to participate.

Ethical Considerations

The proposal for this study was reviewed by the Great Ormond Street Hospital for Children NHS Trust/Institute of Child Health Research Ethics Committee and the East London and The City Health Authority (ELCHA) Research Ethics Sub-Committee. Copies of their letters of approval can be seen in Appendix 4. Copies of extracts from the original Ethics Application forms noting that demographic and health status information would be collected for those who chose not to participate can be seen in Appendix 5.

Recruitment Procedure

Participants were recruited from one national paediatric CF centre (Centre 1) and one regional paediatric CF centre (Centre 2). The two CF Centres involved in the study see their patients at least every three months. Five weeks prior to their appointment, those who met the inclusion criteria were sent an Introductory letter from their lead consultant and an Invitation to Participate from the researcher. Similar letters were sent to their

parent/s or legal guardian/s as all potential participants were under 18 years of age and thus Consent was also required from an adult. The Invitations to Participate provided the rationale for the study and explained the procedure (see Appendices 6 and 7). Participants and their parent/s or legal guardian/s were requested to complete and return a Participation form by post in the stamped, addressed envelope provided, detailing whether or not the adolescent was willing to participate in the study and providing details of how best to make contact in order to arrange an interview time (see Appendix 8). This procedure was repeated over a six-month period, until a minimum sample of 55 had been obtained. This meant that all potential participants from both Centres, who met the inclusion criteria for the study, had a minimum of two opportunities to take part.

Participants

A sample of 55 participants was obtained after seventy-nine potential participants had been approached. This reveals an acceptance rate of 70%. 60% of participants were from Centre 1 and 40% of participants were from Centre 2. 51% of participants were male and 49% were female. A national and a regional centre were targeted for the study in order to evaluate whether there were differences between those who attend national centres and those who attend regional centres. Any observed similarities would inform the generalisability of results.

Inclusion Criteria

Participants were aged between 11 and 17 years, as this is within the age range generally defined as adolescence. The physical, cognitive and psychosocial changes associated with adolescence are typically experienced between the ages of 10 and 20 (Berger, 1987). An age range of 11 to 17 years is incorporated within that, yet is more

homogeneous as it is notably the secondary school years. On a practical level, adolescents are transferred from both paediatric CF centres to adult services by the time they reach 18 years of age. To increase the homogeneity of the sample, only those attending paediatric services were included.

All potential participants had been diagnosed with CF and were registered on the United Kingdom CF database. They were all screened by the lead consultant of each Centre, to ensure that they could speak English to a sufficient standard to complete the questionnaire and the semi-structured interview without assistance. None of the participants were undergoing psychological therapy when they were invited to participate, nor were they being treated for problems associated with their mood.

Exclusion Criteria

Potential participants who had experienced the recent death of a family member less than one year prior to the study were excluded from the study at the request of the ethics committees, as they felt that the psychological distress associated with experiencing bereavement might confound the results of the assessment, specifically relating to self-esteem more so than other life-events.

Data Collection

Participants were invited to participate either directly before or after their clinic appointment, to reduce any inconvenience associated with being involved in the study. After completing the Assent and Consent forms (see Appendices 9 & 10), each participant took part in one assessment session, which lasted between one hour and one and a half hours. All participants were offered regular breaks throughout. All of the

CEDE interviews were audio-taped with the full consent of participants and their parent/s/legal guardian/s, to ensure that all of the information provided was noted and to calculate inter-rater reliability.

Demographic and Health Status Information

General demographic information pertaining to the participant's age, gender and ethnicity was collected from the participants' medical notes. More specific clinical information including weight, height, Body Mass Index (BMI), medications (including enzyme supplementation), current health status and pancreatic status, was also obtained from the medical notes of each participant (see Appendix 11). Different members of the multi-disciplinary team collect the clinical information routinely at each appointment. The same demographic and clinical information was obtained from the medical notes of those who were unwilling to participate to ensure that any potential bias in the sample of participants could be evaluated.

The health status of each potential participant was categorised according to their level of pulmonary function, which is expressed as Forced Expiratory Volume of air in one minute (FEV1) and documented as the percentage obtained out of that predicted for age (Zapletal & Samenek, 1987). Those who obtain a percentage score of 70% or more of that predicted for their age are considered to have mild CF status, a score of 45-69% reflects moderate CF status, whilst a score of 44% or less reflects severe CF status.

In order to determine whether an individual is under weight, DSM-IV (APA, 1994) suggests that individuals should weigh less than 85% of the weight that is considered normal for that person's age and height (Criterion A for AN, see Appendix 1). However,

this does not take into consideration the effects that poor nutrition can have upon growth retardation and upon delayed maturation (Netemeyer & Williamson, 2001), which are commonly seen in the CF population. DSM-IV (APA, 1994) permits the alternative use of a Body Mass Index (BMI) equal to or below 17.5 kg/m² to meet Criterion A. Further it is recommended within the diagnostic criteria for research within the ICD-10 (WHO, 1996). The Body Mass Index (BMI) is calculated as weight in kilograms/ height in metres, squared. The BMI ranges are (Abraham & Llewellyn-Jones, 2001):

- 17.5 or less: Anorexic BMI range (AN BMI Range)
- 17.6-18.9: Under weight
- 19.0-24.9: Desirable BMI range
- 25.0-29.9: Over weight
- 30 or more: Obese ranges

Measures

The Harter/Hoare Self-Esteem Questionnaire (Hoare, Elton, Greer & Kerley, 1993).

This 36-item questionnaire measures global self-esteem as well as five other separate sub-scales, which tap five specific domains: scholastic performance, social acceptance, athletic competence, physical appearance and behaviour. The measure has been standardised on American and British children and adolescents aged from 8 years (Harter, 1985; Hoare et al., 1993). (See Appendix 12 for an explanation of each of the six sub-scales). See Appendix 13 for a copy of the measure.

Each sub-scale has six items, three of which are worded so that the first part of the statement reflects high competence or adequacy, and three of which are worded so that the first part of the statement reflects low competency or adequacy. The participant is asked to place an “X” in the most appropriate of the four boxes provided, for example:

Sort of True for Me	Really True for Me			Sort of True for Me	Really True for Me	
<input type="checkbox"/>	<input type="checkbox"/>	Some kids feel that they are <i>very good</i> at their school work.	BUT	Other kids <i>worry</i> whether they can do the school work assigned to them	<input type="checkbox"/>	<input type="checkbox"/>

The scale represents a continuum of scores. A score of one indicates low perceived competence or adequacy whilst a score of four indicates high perceived competence or adequacy. A score of 2.5 is the mid-point of the scale.

The questionnaire takes approximately 15 minutes to complete. Each sub-scale has good Internal Consistency (Cronbach’s alpha range from 0.71 to 0.86). The measure has been documented to have a high completion rate (approximately 80%), a low refusal rate (less than 1%) and very few spoiled questionnaires (7%), which suggests that it is easy to administer and easy to understand (Hoare et al., 1993). Further the measure is recommended by its authors as useful when examining self-esteem in response to illness.

The Child version of the Eating Disorders Examination (the CEDE) (Bryant-Waugh, Cooper, Taylor & Lask, 1996).

The CEDE has been adapted from the Adult version of the Eating Disorders Examination (the EDE) (Cooper, Cooper & Fairburn, 1989; Cooper & Fairburn, 1987; Fairburn &

Cooper, 1993), which is deemed to be the 'gold standard' for assessing eating disorders (Wilson, 1993). Due to its length a copy of the CEDE has been excluded from the Appendices.

The internal consistency of the sub-scales within the EDE range from 0.67-0.90 (Cooper et al., 1989). Cooper et al. (1989) demonstrated good discriminant reliability using a sample of 100 patients with eating disorders and 42 normal controls. Further, Rosen, Vara, Wendt and Leitenberg (1990) found that the Shape Concern and Weight Concern sub-scales discriminated between patients with Bulimia Nervosa and a group of restrained eaters. There are no reported test-retest reliability studies of the EDE. Cooper and Goodyer (1994) utilised the EDE with 400 eleven to sixteen year olds and concluded that this instrument was utilised with such an age group without difficulty. However, they noted that particular care was required for younger participants on some items. The CEDE has four modifications, which were made in an attempt to make the EDE a more reliable tool for children and adolescents. These will be described after a broad description of the CEDE.

The CEDE is a present state, semi-structured, investigator-based interview schedule designed to assess and diagnose the specific psychopathology of eating disorders in children and adolescents aged from eight years of age. It produces information concerning the four weeks leading up to the interview. However, some of the questions ask about the previous three months so that sufficient information can be gained to satisfy the DSM-IV criteria. Whilst the interviewer must ask each of the questions within the CEDE, s/he can also question further in order to clarify the concept under

investigation.

The CEDE provides either frequency or severity ratings for key behavioural and attitudinal aspects related to eating disorders. The measure produces operationally defined eating disorder diagnoses for Anorexia Nervosa (AN), Bulimia Nervosa (BN) and A-Typical eating disorders, based upon the DSM-IV criteria (APA, 1994). The questions pertinent to a formal diagnosis are termed 'The Diagnostic sub-scale'. On both frequency and severity ratings, scores range from 0-6. Within the Diagnostic sub-scale, scores of 4-6 meet diagnostic criteria, whilst scores of 2-3 reveal 'eating disturbance', as the individual shows symptomatology but not to the standard required for a diagnosis. Such scores have been termed 'sub-threshold' scores. Scores of 0-1 reflect concerns within the 'normal' range as determined by Bryant-Waugh et al. (1996).

The administration of the CEDE also produces individual scores as well as sub-scale scores for four other non-diagnostic sub-scale categories: Restraint, Eating Concern, Shape Concern and Weight Concern so that the nature of any concerns can be examined. Scores of 2-6 on these four sub-scale categories have been termed 'positive' scores to ease clarification, as they are utilised for descriptive purposes only. The CEDE takes approximately one hour to complete and interviewers are required to complete a two-day training course before they are permitted to utilise the tool.

The four modifications made to the EDE to produce the CEDE are:

1. Parents and children or adolescents are asked to complete a food diary for one month prior to the interview. They are also asked to complete a 'Significant Events' diary for

that month and retrospectively over the two preceding months. Both diaries are given to the child or adolescent at the beginning of the interview and used as a memory cue to facilitate the reliability of their responses.

2. The language of the CEDE has been altered to ensure that it is more comprehensible for children as young as eight years of age.

3. The CEDE asks about the child's *intentions* as well as their actual behaviours. Parents or carers often control the eating behaviours of children and adolescents and thus the measure attempts to ascertain what behaviours the child or adolescent might engage in when unsupervised. The attempt to carry out behaviours are utilised to calculate scores, not just actual behaviours.

4. Two key items, namely Shape Importance and Weight Importance, are administered as a card sort task rather than asking the extent to which they are important in terms of self-evaluation. Children and adolescents are therefore asked to write down five or six things that are important to them in how they judge themselves. If they have not included body Shape or Weight, the interviewer adds them to their list and then they are asked to put all of the items in order of importance to them over the last four weeks and then, separately, over the two preceding months. Bryant-Waugh et al. (1996) felt this change was necessary as the formulation of these two issues requires an ability to think in abstract, self-evaluative terms, and younger children may have found the adult administration of this task particularly difficult.

Bryant-Waugh et al. (1996) piloted the CEDE on sixteen children aged between 7 and 14 years, attending an eating disorders clinic. The sub-scale scores obtained were consistent with those obtained with adult patients utilising the EDE and were also consistent with clinical observation. Frampton (1996) interviewed 30 clinical participants and 30 normal controls between the ages of eight and 14 year. He found that children who were given a clinical diagnosis of AN, virtually mirrored the sub-scale scores of the adult AN standardised sample (Cooper & Fairburn, 1987). Bryant-Waugh et al. (1996) thus conclude that the CEDE is a useful tool for the assessment and diagnosis of eating disorders and eating disturbance in children and adolescents.

Bryant-Waugh (personal communication, 2001) states that although the CEDE has been validated on children and young adolescents aged between 8 and 14 years, it can be utilised with adolescents up to the age of 17 as the measure has been adapted to ensure that the younger children can understand the questions. Although the measure has not been validated on adolescents aged 15 to 17, it is unlikely that they will experience any difficulty comprehending the questions and thus will not find it problematic. Further the CEDE is utilised regularly in clinical practice for assessment and diagnostic purposes and for evaluating therapeutic change in children and adolescents up to the age of 17 in both of the hospitals where this study took place.

The use of the CEDE within this study

The CEDE has not been used within the CF population to date. However, Fairburn, Peveler, Davies, Mann and Mayou (1991) used the EDE with an adult diabetic population, which is a disease that also focuses upon nutrition as part of treatment and

where medication might also be utilised to facilitate weight loss. Utilising the following adaptations, Fairburn et al. (1991) concluded that they were able to reliably distinguish eating disorder psychopathology from similar behaviours that were motivated by having diabetes and the demands of treatment. These adaptations were therefore utilised for the purpose of this study:

Their interviewers ensured that they clarified the reasons behind behaviours and attitudes, for example:

- *Over the past four weeks have you deliberately been trying to cut down on what you eat, even if you haven't managed this?*
- *Why have you done this?*
- *Have you done this to try to change your shape or your weight?*
- *How often have you done this?*

Participants scored from one to six dependent upon the frequency of this particular behaviour *only* if the behaviour was related to body shape or weight. The present study also clarified responses in this way to ensure that responses were not motivated by CF.

Fairburn et al. (1991) also included an additional question concerning the under-use or omission of insulin for the purpose of weight control. This question was adapted for the purpose of the present study:

- *Over the past four weeks have you deliberately been trying to cut down on your treatments for your CF, even if you haven't managed this?*

- *Why have you done this?*

-*How often have you done this?*

Attempts at restraint from treatment were only rated if the treatment restrained from was pancreatic enzyme medication and the reasons for restraint were associated with body shape or weight.

Procedural issues related to the use of the CEDE within this study

Reluctance by the first 10 participants and their parents to complete either of the diaries meant that, instead, time was spent at the beginning of each interview completing a diary of significant events over the preceding three months and questioning participants about their appetite over the preceding four weeks in order to facilitate their recollection of events and to orient them to the time span in question.

The inter-rater reliability of the use of the CEDE within this study was assessed by carrying out Pearson's bivariate correlations between the researcher and a second, trained rater who had listened to tapes of 20 interviews, which had been randomly selected. The correlations ranged from 0.69 to 1. Current standards in research suggest that a correlation of 0.6 reflects adequate inter-rater reliability and a correlation of 0.8 is good (Barker, Pistrang & Elliot, 1994). The inter-rater reliability of the CEDE within this research project can therefore be considered to be satisfactory for the purpose of quantitative analyses.

CHAPTER 3

RESULTS

Overview

The demographic information obtained for the participants and for those who did not wish to participate will be presented first, followed by the analyses that were conducted to examine the research questions and hypotheses of the study, in turn. Some further analyses will then be presented, which were carried out in an attempt to address additional issues that arose from the study.

Chi-square tests were utilised to analyse categorical data. Continuous data were tested for normality and for homogeneity of variance. None of the demographic variables differed significantly from normality. However, when examining the CEDE sub-scale categories, one case was 4.9 standard deviations from the mean within 'Weight Concern'. This case was a distinct outlier from any of the other cases and was therefore excluded from the analyses of the sub-scale categories. Parametric statistics were utilised to analyse the continuous data.

Demographic Information

Table 3-1 describes the age, gender, ethnicity, Body Mass Index ranges (BMI), the number who were undergoing enteral feeding as well as the health and pubertal status of participants from the two CF Centres. 82% and 77% of participants from Centres 1 and 2 respectively were White British/UK, which reflects the increased prevalence of CF in the Caucasian population (Green, 1996). 49% and 41% of the sample from each Centre respectively had Body Mass Index Scores of less than or equal to 17.5, which falls within the Anorectic range (AN BMI range) (Abraham & Llewellyn-Jones, 2001). The majority

of participants had mild CF, reflecting a Forced Expiratory Volume of air in one minute (FEV1) of 70% or above that predicted for age. Approximately 50% of the sample was post pubertal. There were no significant differences between the two CF centres on any of the demographic variables listed in Table 3-1, which suggests that this sample is representative of an adolescent CF population in general.

Table 3-1

The demographic information of those who participated in the study

PARTICIPANTS				
Demographic Variables	Centre 1 (N= 33)	Centre 2 (N= 22)	Statistic	p-value
Mean age in Years SD, Range	14.2 1.55, 11-16.6	14.14 2.15, 11-17.3	t (53)= 0.12	0.90
Gender n (%) female	17 (51.5)	10 (45.5)	$\chi^2(1)= 0.19$	0.66
Ethnicity n (%) White British/UK	27 (81.8)	17 (77.3)	$\chi^2(1)= 0.17$	0.68
Mean BMI SD, Range	18.1 2.35, 14.5-23.4	18.6 2.86, 13.2-24.1	t (39)= 0.80	0.43+
AN BMI range n (%) Desirable BMI range n (%)	16 (48.5) 17 (51.5)	9 (40.9) 13 (59.1)	$\chi^2(1)= 0.31$	0.58
Enteral Feeding n (%) yes	5 (15.2)	7 (31.8)	$\chi^2(1)= 2.15$	0.14
Health Status n (%) mild n (%) severe	25 (75.8) 8 (24.2)	19 (86.4) 3 (13.6)	$\chi^2(1)= 0.93$	0.34
Pubertal Status n (%) pre puberty n (%) post puberty	15 (45.5) 18 (54.5)	12 (54.5) 10 (45.5)	$\chi^2(1)= 0.44$	0.51

† Equal Variances not assumed.

Table 3-2 compares male participants with female participants on the demographic variables described above to examine whether there were significant gender differences. Whilst there were no significant differences between male and female participants on any of the demographic variables, more male participants had BMI scores that fell within the AN BMI range (Abraham & Llewellyn-Jones, 2001) and were under-going enteral feeding consequent to inadequate weight gain or weight loss over a three-month period.

Table 3-3 examines the mean self-esteem scores obtained by the male and female participants. There was a significant gender difference within the self-esteem sub-scale 'athletic competence'. Gender differences therefore need to be considered as a possible confounding variable in the analyses of self-esteem. Although gender differences between the other sub-scales were non-significant, the male participants obtained higher mean scores on athletic competence and physical appearance, whilst the female participants obtained higher mean scores on behaviour. Male participants' mean scores did not fall below the mid-point in any of the domains, whilst the mean scores for female participants fell at the mid-point or below for physical appearance and athletic competence respectively.

Table 3-4 compares the participants from both CF centres with those who did not wish to participate, on the demographic variables described above. No significant differences were found. However the mean BMI score for non-participants was lower than for participants but fewer non-participants fell within the AN BMI range or were under-going enteral feeding.

Table 3-2

The Demographic Information of Male participants in comparison to Female participants

PARTICIPANTS				
Demographic Variables	Male (n=28)	Female (n= 27)	Statistic	p-value
Mean Age in Years SD, Range	14.20 1.96, 11-17.3	14.10 1.64, 11-17.0	t (52)= 0.29	0.77†
Ethnicity n (%) White British/UK	20 (71.4)	24 (88.9)	$\chi^2(1)= 2.62$	0.11
Mean BMI SD, Range	18.1 2.69, 13.2-24.1	18.5 2.45, 14.9-22.8	t (53)= 0.58	0.57†
AN BMI n (%)	14 (50.0)	11 (40.7)		
Desirable BMI n (%)	14 (50.0)	16 (59.3)	$\chi^2(1)= 0.48$	0.49
Enteral Feeding n yes (%)	8 (28.6)	4 (14.8)	$\chi^2(1)= 0.65$	0.42
Health Status n (%) mild	21 (75.0)	23 (85.2)		
n (%) severe	7 (25.0)	4 (14.8)	$\chi^2(1)= 0.89$	0.35
Pubertal Status n (%) pre pubertal	14 (50.0)	13 (48.2)		
n (%) post pubertal	14 (50.0)	14 (51.9)	$\chi^2(1)= 0.02$	0.89

† Equal Variances not assumed.

Table 3-3

The Self-Esteem Scores obtained by Participants

PARTICIPANTS				
Mean Scores	Male (n= 28)	Female (n= 27)	Statistic	p-value
Global Self-Esteem SD, Range	3.1 0.50, 1.7-3.8	3.0 0.64, 2.0-4.0	t (53)= 0.82	0.42
Scholastic Performance SD, Range	2.8 0.62, 1.67-4.0	2.9 0.66, 1.3-3.8	t (52)= 0.49	0.63+
Social Acceptance SD, Range	3.1 0.69, 1.5-4.0	3.2 0.62, 1.3-4.0	t (53)= 0.44	0.66+
Athletic Competence SD, Range	2.8 0.79, 1.0-4.0	2.3 0.78, 1.0-4.0	t (53)= 2.65	0.01+
Physical Appearance SD, Range	2.8 0.63, 1.7-4.0	2.5 1.2-3.8	t (53)= 1.62	0.11+
Behaviour SD, Range	3.0 0.67, 1.5-4.0	3.3 0.57, 1.8-4.0	t (52)= 1.91	0.06+

† Equal Variances not assumed.

Table 3-4

The Demographic Information of Participants in comparison to Non-Participants

Demographic Variables	Participants (N = 55)	Non-Participants (N= 24)	Statistic	p-value
Mean Age in Years SD, Range	14.2 1.8, 11-17.3	14.0 2.0, 11-17.6	t (40)= 0.33	0.74†
Gender n (%) female	27 (49.1)	12 (50.0)	$\chi^2(1)= 0.06$	0.94
Ethnicity n (%) White British/UK	44 (80.0)	22 (91.7)	$\chi^2(1)= 1.65$	0.20
Mean BMI SD, Range	18.3 2.6, 13.2-24.1	18.1 2.4, 13.8-21.4	t (48)= 0.37	0.71†
AN BMI range n (%)	25 (45.6)	9 (37.5)	$\chi^2(1)= 0.43$	0.51
Desirable BMI range n (%)	30 (54.6)	15 (62.5)		
Enteral Feeding n (%) yes	12 (21.8)	3 (12.5)	$\chi^2(1)= 0.94$	0.33
Health Status n (%) mild	44 (80.0)	20 (83.3)	$\chi^2(1)= 0.12$	0.73
n (%) severe	11 (20.0)	4 (16.7)		
Pubertal Status n (%) pre-pubertal	27 (49.1)	13 (54.2)	$\chi^2(1)= 0.17$	0.68
n (%) post-pubertal	28 (50.9)	11 (45.8)		

† Equal Variances not assumed.

IN SUMMARY

There were no significant differences between the two CF Centres on any of the demographic variables examined nor were there any significant differences between male and female participants or between participants and non-participants on any of the demographic variables examined. However there was one significant difference between male and female participants on the athletic competence self-esteem sub-scale only.

Examination of the Research Questions and Hypotheses

Eating Disorders

Qu. 1a) What are the nature and prevalence of formal eating disorders in adolescents with Cystic Fibrosis?

In order to fulfil the DSM-IV diagnostic criteria for Anorexia Nervosa (AN) (DSM-IV, APA, 1994) females must meet criteria A-D and males must meet criteria A-C. (See Appendix 1). Table 3-5 represents the diagnostic criteria for AN and the number and percentage of participants who met each individual criterion. None of the participants met all of the criteria for AN. However, for those whose weight fell within the Anorectic BMI range (the AN BMI range), of particular interest is evidence of attempts to maintain low weight through avoiding weight gain in three participants. This is 12% of the AN BMI sub-sample and 5% of the total sample. One participant denied the seriousness of her low weight, as she felt fat despite her low weight status. Both male and female participants felt that their body shape or weight influenced self-evaluation unduly (Criterion C).

Table 3-5

The number and percentage of participants who met the individual criteria for AN (DSM-IV, APA, 1994)

PARTICIPANTS		
AN BMI Range		
AN Criteria	Male (n= 14)	Female (n= 11)
A. *Maintained low weight in those within the AN BMI range by:		
- Attempting to lose weight n (%)	0	0
or - Attempting to avoid weight gain n (%)	2 (14.3)	1 (9.1)
B. *Intense fear of weight gain n (%)	0	0
C. *Importance of Shape n (%)	2 (14.3)	1 (9.1)
or *Importance of Weight n (%)	3 (21.4)	3 (27.3)
or *Denial of seriousness of low body weight n (%)	0	1 (9.1)
D. Amenorrhea where appropriate	N/A	0
Restricting Type: n (%)	0	0
Binge-Eating/Purging Type: n (%)	0	0

* All those required for a diagnosis of AN for males.

N/A: Not applicable

In order to fulfil the DSM-IV diagnostic criteria for Bulimia Nervosa (BN) (DSM-IV, APA, 1994) females and males must meet criteria A-E. The full diagnostic criteria can be seen in Appendix 2. Table 3-6 represents the diagnostic criteria for BN and the number and percentage of participants who met each individual criterion. Whilst none of these participants (whose weight fell within the Desirable BMI range) met all of the criteria for BN, there is evidence of the misuse of pancreatic enzyme medication to facilitate weight loss in one female participant. Both male and female participants felt that their body shape or weight had an undue influence upon their self-evaluation.

The diagnostic criteria for Eating Disorders Not Otherwise Specified (EDNOS) (DSM-IV, APA, 1994) can be seen in Appendix 3. Table 3-7 represents the diagnostic criteria for EDNOS and the number and percentage of participants who met each individual criterion. The table reveals that one male participant met the criteria for EDNOS as he met all of the criteria for AN but his weight fell within the Desirable BMI range. This is 4% of the male sub-sample and 2% of the total sample.

Table 3-6: The number and percentage of participants who met the individual criteria for BN (DSM-IV, APA, 1994)

PARTICIPANTS		
Desirable BMI Range		
BN Criteria	Male (n= 14)	Female (n= 16)
A. *Recurrent episodes of binge eating n (%)	0	0
B. *Any one of the following inappropriate compensatory Behaviours:		
- Self-induced vomiting n (%)	0	0
- Laxative Misuse n (%)		
- Diuretic Misuse n (%)	0	0
(- Other Medication misuse (pancreatic enzymes) n (%)	0	1 (6.3)
- Fasting n (%)	0	0
- Intense exercising n (%)	0	0
C. *		
D. Importance of Shape n (%)	3 (21.4)	1 (6.3)
or Importance of Weight n (%)	2 (14.3)	0
E. **		
Purging Type	0	0
Nonpurging Type	0	0

*Criteria A and B are met only if they meet Criterion C: A & B must both occur at least twice per week for three months

**Criteria A, B, C & D are met only if they meet Criteria E: The disturbance does not occur exclusively during episodes of AN

Table 3-7

The number and percentage of participants who met each of the individual criteria for EDNOS (DSM-IV, APA, 1994)

EDNOS Criteria	GENDER			
	Desirable BMI Range		AN BMI Range	
	Male (n= 14)	Female (n= 16)	Male (n= 14)	Female (n= 11)
1. For females, all of the criteria for AN but regular menses are maintained n (%)	N/A	0	N/A	0
2. All of the criteria for AN except weight is within the normal range n (%)	1 (7.1)	0	0	0
3. All of the criteria for BN except compensatory behaviours are less frequent n (%)	0	0	0	0
4. Use of compensatory behaviour after eating small amounts of food n (%)	0	0	0	0
5. Repeatedly chewing and spitting out of large amounts of food n (%)	0	0	0	0
6. Binge-Eating Disorder	0	0	0	0

AN: Summary of those who met criterion A

Two males and one female met Criterion A for AN as they were all actively attempting to avoid weight gain despite their weight falling within the AN BMI range. None of them met Criterion B. However one male participant obtained sub-threshold scores for Criterion B as his fear of weight gain was not frequent enough for diagnostic purposes. The female participant met diagnostic criteria for Criterion C. Both shape and weight had an undue influence upon her self-evaluation. She obtained sub-threshold scores for denying the seriousness of her current low body weight as she felt fat on occasion but not frequently enough for diagnostic purposes. She had amenorrhea for one month only. Both of the male participants obtained sub-threshold scores for Criterion C for body Shape and Weight Importance, but neither of them felt fat, suggesting that they were both aware of their weight status. Both male participants were pre-pubertal.

BN: Summary of those who met criterion B

One female participant met Criterion B as she had reduced the amount of enzyme medication that she was prescribed every day over a three-month period, in order to reduce her weight. She met the diagnostic criteria for Shape Importance and obtained a sub-threshold score for Weight Importance, suggesting that her shape played a more important role than her weight, regarding her self-evaluation.

IN SUMMARY:

Tables 3-5 and 3-6 reveal that both male and female participants met some of the criteria for individual symptoms relating to both AN and BN. However none of the participants met all of the criteria for either AN or BN, which precludes the diagnosis of either of

these eating disorders within this sample. One male participant met the criteria for EDNOS. This reflects an EDNOS prevalence rate of 2% within this sample.

Hypothesis 1a) Adolescents with eating disorders are more likely to experience symptoms related to Anorexia Nervosa such as restraint from eating than symptoms related to Bulimia Nervosa such as bulimic episodes.

This could not be evaluated as only one participant was diagnosed with a formal eating disorder.

Qu. 2a) How does the prevalence of eating disorders in this sample compare to the general adolescent population and the diabetic adolescent population?

The prevalence of AN and BN is 0% in this adolescent sample in comparison to a prevalence rate of approximately 1% for AN (APA, 1994) and 1-3% for BN (Carr, 1999) in the general adolescent population. One male adolescent met the diagnostic criteria for EDNOS, which indicates a prevalence rate of 2% of the total sample. Killen et al. (1994) documented a prevalence rate of 4% for EDNOS in their female adolescent population but to date prevalence rates of EDNOS for male adolescents have not been documented within the literature.

One female participant documented pancreatic enzyme misuse as a weight loss measure, which reflects a prevalence rate of 2% within this sample. Within the Insulin Dependent Diabetes Mellitus (IDDM) population, patients are able to facilitate weight loss through

the manipulation of treatments, for example withholding insulin. Prevalence rates of insulin misuse as a weight loss measure have been estimated at between 12-39% within the female IDDM population (Stancin, Link & Reuter, 1989; Rodin, Cravin & Littlefield, 1991). This reflects a greater prevalence of medication misuse within the IDDM population than within this CF sample.

Qu. 3a) How do a group of adolescents with CF and eating disorders compare with a matched group from the same population with CF but without eating disorders on a range of variables, including demographic variables, self-esteem and variables related to eating?

None of the sample had AN or BN and only one male participant fulfilled the criteria for EDNOS. Consequently a comparison with a matched group from the same population with CF but without eating disorders on a range of different variables was not possible.

Hypothesis 2a) Eating disorders will be evident in adolescents with CF irrespective of the severity of their condition.

This could not be evaluated as only one participant was diagnosed with a formal eating disorder.

Hypothesis 3a) The presence or absence of symptoms associated with eating disorders will be related to differences in gender.

This could not be evaluated as only one participant was diagnosed with a formal eating disorder.

Hypothesis 4a) The presence or absence of symptoms associated with eating disorders will be related to differences in self-esteem.

This could not be evaluated as only one participant was diagnosed with a formal eating disorder.

Eating Disturbance

Qu 1b) What is the nature and prevalence of eating disturbance in adolescents with Cystic Fibrosis?

Tables 3-8 and 3-9 examine the number and percentage of participants whose weight fell within both the Desirable BMI range and the AN BMI range, who obtained sub-threshold scores on each of the individual diagnostic criteria for AN and BN respectively. Sub-threshold scores reveal evident symptomatology but not of the frequency or severity required for a formal diagnosis. Due to the danger associated with any attempts to restrain from weight gain or attempt weight loss, it was felt necessary to examine anorectic symptomatology in those whose weight fell within the Desirable BMI range, as

well as in those whose weight fell within the AN BMI range. The nature of the diagnostic criteria for EDNOS precludes examination of sub-threshold scores and this has therefore been excluded.

Table 3-8

The number and percentage of participants who obtained sub-threshold scores on each of the individual diagnostic criteria for AN (DSM-IV, APA, 1994

AN Criteria	GENDER			
	Desirable BMI Range		AN BMI Range	
	Male (n= 14)	Female (n= 16)	Male (n= 14)	Female (n= 11)
A. *Maintained weight:				
- Attempting to lose weight n (%)	1 (7.1)	3 (18.8)	/	/
or - Attempting to avoid weight gain n (%)	1 (7.1)	1 (6.3)	/	/
B. *Fear of weight gain n (%)	0	2 (12.5)	0	0
C. *Importance of Shape n (%)	4 (28.6)	7 (43.8)	4 (28.6)	2 (18.2)
or Importance of Weight n (%)	4 (28.6)	11 (68.8)	6 (42.9)	2 (18.2)
or Denial of weight status n (%)**	2 (14.3)	3 (18.8)	0	0
D. Irregular Menstruation n (%)	N/A	2 (12.5)	N/A	1 (9.1)
Restricting Type Symptoms: n (%)	2 (14.3)	4 (25.0)	0	0
Binge-Eating/Purging Type: Symptoms n (%)	0	1 (6.3)	0	0

/: Participants within the AN BMI range who attempt to maintain their weight meet diagnostic criteria for AN

* All those required for a diagnosis of AN for males. ** These participants felt fat

N/A: Not applicable

Table 3-8 reveals that, within the Desirable BMI range sub-sample, six participants were attempting to maintain their current weight status. This is 20% of the Desirable BMI range sub-sample and 11% of the total sample. Two participants feared weight gain, although its intensity did not meet diagnostic criteria. This is 4% of the total sample. More female participants felt that their body weight influenced their self-evaluation than their body shape. This difference was not apparent within the male sub-sample. Five participants felt fat although their weight was within the Desirable BMI range.

Table 3-8 also shows that, within the AN BMI sub-sample, more male participants than female participants felt that their body shape or weight influenced their self-evaluation. This was particularly evident relating to body weight.

Table 3-9 reveals that two participants whose weight fell within the Desirable BMI range were exercising to prevent weight gain, but not intensively enough for diagnostic purposes. This is 7% of the Desirable BMI sub-sample and 4% of the total sample. More female participants felt that their body weight rather than their body shape influenced their self-evaluation.

Table 3-9: The number and percentage of participants who obtained sub-threshold scores for BN (DSM-IV, APA, 1994)

AN Criteria	GENDER	
	Male (n= 14)	Female (n= 16)
Desirable BMI Range		
A. *Recurrent episodes of binge eating n (%)	0	0
B. *Any one of the following inappropriate compensatory behaviours:		
- Self-induced vomiting n (%)	0	0
- Laxative Misuse n (%)	0	0
- Diuretic Misuse n (%)	0	0
- Other Medication misuse (pancreatic enzymes) n (%)	0	0
- Fasting n (%)	0	0
- Intense exercising n (%)	1 (7.1)	1 (6.3)
C. N/A*		
D. Importance of Shape n (%)	3 (21.4)	6 (37.5)
or Importance of Weight n (%)	3 (21.4)	11 (68.8)
E. **		
Purging Type	0	0
Nonpurging Type	1 (7.1)	1 (6.3)

* Criteria A & B do not occur at least twice per week for three months.

** Criteria A & B are met if disturbance does not occur exclusively during episodes of AN

IN SUMMARY:

Behaviours: For those whose weight fell within the Desirable BMI range, six participants were attempting to either lose weight or avoid weight gain, which reflects 20% of the Desirable BMI range sub-sample and 11% of the total sample. Two participants were exercising for reasons to do with their weight and shape. This is 7% of this sub-sample and 4% of the total sample. One participant described binge-eating behaviour over a two-month period, whilst trying to restrain her eating. Restricting-type behaviours were therefore evident in 11% of the total sample whilst binge-eating type behaviours were evident in one participant.

Attitudes: For of those whose weight fell within the Desirable BMI range two participants feared weight gain. Eleven participants felt that their body shape influenced their self-evaluation, whilst 15 participants felt that their body weight influenced their self-evaluation. This reflects 37% and 50% of this sub-sample and 20% and 27% of the total sample respectively. For those whose weight fell within the AN BMI range, there was no evident fear of weight gain. However six participants felt that their body shape was important to them regarding their self-evaluation, whilst eight participants felt that their body weight was important to them regarding their self-evaluation. This represents 24% and 32% of the AN BMI range sub-sample and 11% and 15% of the total sample respectively.

If one considers all of those participants who either met criteria or obtained sub-threshold scores for AN out of the total sample, nine participants (16%) were attempting to maintain their weight as it was, of which 3 (5%) were participants whose weight fell

within the AN BMI range. Two participants (4%) had some fear about weight gain, none of whom fell within the AN BMI range. 20 participants (36%) felt that their body shape influenced their self-evaluation, of which 9 (16%) were participants whose weight fell within the AN BMI range, whilst 29 participants (53%) felt that their body weight influenced their self-evaluation of which 14 (25%) were participants whose weight fell within the AN BMI range. Six participants (11%) (none of whom were over weight) felt fat. One female participant reported binge-eating over a two-month period whilst trying to restrain her eating.

If one considers all of the participants who either met criteria or obtained sub-threshold scores for BN, three participants (10%) were utilising compensatory behaviours such as exercising or misusing pancreatic enzyme medication to facilitate weight loss. This is 5% of the total sample. 13 (43%) and 16 (53%) of participants respectively felt that their body shape or weight influenced their self-evaluation. This is 24% and 29% respectively of the total sample.

Hypothesis 1b) Adolescents with eating disturbance are more likely to experience symptoms related to Anorexia Nervosa such as restraint from eating rather than symptoms related to Bulimia Nervosa such as bulimic episodes.

It is evident from the Summary described above that adolescents within this sample are unlikely to binge-eat. However a minority do attempt to either lose weight or avoid weight gain and utilise compensatory behaviours such as exercise due to concerns regarding their shape and/or weight. This suggests that Hypothesis 1b can be cautiously confirmed.

Qu 2b) How does the prevalence of eating disturbance in this sample compare to the general adolescent population and the diabetic adolescent population?

Within this current sample 11% of participants felt fat and 4% feared weight gain, which is lower than findings within the general adolescent population. Childress et al. (1993) report feelings of fatness in 40% of 3,129 9-16 year olds. Body shape was felt to be of significant importance to the self-evaluation of 24% and 36% of participants within the Desirable BMI range and the AN BMI range respectively, whilst body weight was felt to be of significant importance to the self-evaluation of 29% and 53% respectively. Studies examining the importance of body shape and weight to self-evaluation in the general adolescent population are not evident in the literature.

In total 40 participants showed eating disturbance within the present study. This is 73% of the total sample. Affenito et al. (1997) found a prevalence rate of 14% in their sample of 90 diabetic participants. However they utilised DSM-III-R criteria (APA, 1987). The present study utilised a tool based upon DSM-IV (APA, 1994), which is a more recent version of this classification system, rendering it difficult to make any firm comparisons.

The nature of eating disturbance

In order to examine the exact nature of eating disturbance in this sample in more detail, Table 3-10 examines the number and percentage of participants who obtained positive scores on each of the questions within the other four sub-scale categories within the CEDE. Positive scores within the four non-diagnostic sub-scale categories reflect scores of two and above. This equates with both 'sub-threshold' and diagnostic scores within

the 'diagnostic' sub-scale category. They have been named differently to ease clarification, as they are not utilised for diagnostic purposes.

Restraint: None of the male participants whose weight fell within the AN BMI range were restraining from eating for reasons to do with shape or weight, but restraint was evident in females whose weight fell within the AN BMI range. Restraint was particularly evident in the female participants whose weight fell within the Desirable BMI range.

Eating Concern: Male participants within the Desirable BMI range and female participants within the AN BMI range did not appear to have eating concerns but there was a trend towards increased concerns in females within the Desirable BMI range and males within the AN BMI range.

Shape Concern: Two participants whose weight fell within the AN BMI range were dissatisfied that their shape was too large. This represents 8% of the AN BMI subsample and 4% of the total sample. Six male participants who were dissatisfied that their shape was too small fell within the AN BMI range, which reflects 24% of this subsample and 11% of the total sample, whilst only two female participants who were dissatisfied that their shape was too small fell within this range. More female participants whose weight fell within the Desirable BMI range felt that their body shape was important to them in comparison to females within the AN BMI range. Shape was important to males irrespective of BMI status. Few participants felt uncomfortable looking at their own bodies due to concern about their overall appearance. However four

participants avoided showing their bodies in front of others as they felt that their overall appearance was too big. Less participants whose weight fell within the AN BMI range had strong desires for a flat stomach, not merely a flatter stomach, than those whose weight fell within the Desirable BMI range.

Weight Concern: Nine participants were dissatisfied that their weight was too heavy, two of whom fell within the AN BMI range, which is 16% of the total sample and 13% of the AN BMI sub-sample. In total 17 (31%) participants were dissatisfied that their weight was too light, although fewer females who fell within the AN BMI range were dissatisfied about this than males. There was a strong desire to lose weight in five participants (9%), two of whom fell within the AN BMI range. Female participants whose weight fell within the AN BMI range did not appear to be as concerned about prescribed, weekly weighing than male participants or any of the participants whose weight fell within the Desirable BMI range. Despite evident concerns about weight, only one male and one female participant felt that their weight preoccupied them, thus effecting concentration on other things. In total 29 (53%) participants felt that their body weight influenced their self-evaluation. This was particularly evident in the female participants whose weight fell within the Desirable BMI range.

Table 3-10: The Percentage of Participants who obtained positive scores on the individual items of the CEDE

CEDE Sub-Scale Category scores	GENDER			
	Desirable BMI Range		AN BMI Range	
	Male (n= 14)	Female (n= 16)	Male (n= 14)	Female (n= 11)
RESTRAINT:				
- Restraint over Eating n (%)	1 (7.1)	3 (18.8)	0	1 (9.1)
- Avoidance of Eating n (%)	1 (7.1)	1 (6.3)	0	0
- Empty Stomach n (%)	0	2 (12.5)	0	1 (9.1)
- Food Avoidance n (%)	0	3 (18.8)	0	1 (9.1)
- Dietary Rules n (%)	0	2 (12.5)	0	1 (9.1)
EATING CONCERN:				
- Preoccupation with Food n (%)	1 (7.1)	0	1 (7.1)	0
- Fear of Losing Control over Eating n (%)	0	1 (6.3)	0	0
- Social Eating n (%)	0	1 (6.3)	2 (14.3)	0
- Eating in Secret n (%)	0	0	0	1 (9.1)
- Guilt after Eating n (%)	0	2 (12.5)	0	0

Table 3-10 Cont'd

The Percentage of Participants who obtained positive scores on the individual items of the CEDE

CEDE Sub-Scale Category scores	GENDER			
	Desirable BMI Range		AN BMI Range	
	Male (n= 14)	Female (n= 16)	Male (n= 14)	Female (n= 11)
SHAPE CONCERN:				
- Dissatisfaction with Shape				
Shape is too large				
n (%)	4 (28.6)	4 (25.0)	1 (7.1)	1 (9.1)
or				
Shape is too small				
n (%)	0	2 (12.5)	6 (42.9)	2 (18.2)
- Preoccupation with Shape				
n (%)	1 (7.1)	1 (6.3)	0	0
- Importance of Shape				
n (%)	7 (50.0)	8 (50.0)	6 (42.9)	3 (27.3)
- Fear of Weight Gain				
n (%)	3 (21.4)	3 (18.8)	0	0
- Discomfort Seeing Body				
Feels overall appearance				
is too big				
n (%)	1 (7.1)	1 (6.3)	0	2 (18.2)
or				
Feels overall appearance				
is too small				
n (%)	1 (7.1)	1 (6.3)	1 (7.1)	1 (9.1)
- Avoidance of Exposure				
Feels overall appearance				
is too big				
n (%)	2 (14.3)	1 (6.3)	0	1 (9.1)
or				
Feels overall appearance				
is too small				
n (%)	1 (7.1)	2 (12.5)	1 (7.1)	2 (18.2)
- Feelings of Fatness				
n (%)	3 (21.4)	2 (12.5)	0	1 (9.1)
- Flat Stomach				
n (%)	5 (35.7)	3 (18.8)	2 (14.3)	2 (18.2)

Table 3-10 Cont'd

The Percentage of Participants who obtained positive scores on the individual items of the CEDE

CEDE Sub-Scale Category scores	GENDER			
	Desirable BMI Range		AN BMI Range	
	Male (n= 14)	Female (n= 16)	Male (n= 14)	Female (n= 11)
WEIGHT CONCERN:				
- Dissatisfaction with Weight				
Feels weight is too high				
n (%)	1 (7.1)	6 (37.5)	0	2 (18.2)
or Feels weight is too low				
n (%)	3 (21.4)	3 (18.8)	7 (50.0)	4 (36.4)
- Desire to Lose Weight				
n (%)	1 (7.1)	2 (12.5)	0	2 (18.2)
- Reaction to Prescribed Weighing				
n (%)	4 (28.6)	5 (31.3)	4 (28.6)	2 (18.2)
- Preoccupation with Weight				
n (%)	1 (7.1)	1 (6.3)	0	0
- Importance of Weight				
n (%)	6 (42.9)	11 (68.8)	4 (28.6)	8 (72.7)

Table 3-11 examines the global scores obtained for each of the four sub-scale categories described in Table 3-10. The global scores reflect the mean score of all questions within the sub-scale where a score of two or more was obtained. There were no significant differences between male and female participants on any of the sub-scale categories.

Table 3-11

The global scores obtained in the four sub-scale categories of the CEDE

GENDER				
Global Sub-Scale Category scores	Male (n= 28)	Female (n= 27)	Statistic	p-value
RESTRAINT SD, range	0.04 0.17, 0.0-0.8	0.22 0.70, 0.0-3.0	t (52)= 1.32	0.19
EATING CONCERN SD, Range	0.07 0.18, 0.0-0.6	0.08 0.20, 0.0-0.8	t (51)= 0.11	0.92+
SHAPE CONCERN SD, Range	0.34 0.63, 0.0-2.6	0.29 0.65, 0.0-2.6	t (51)= 0.29	0.77+
WEIGHT CONCERN SD, Range	0.51 0.49, 0.0-1.4	0.61 0.72, 0.0-3.0	t (43)= 0.59	0.55+

† Equal Variances not assumed.

Qu 3b) How do a group of adolescents with CF and eating disturbance compare with a matched group from the same population with CF but without eating disturbance on a range of variables including demographic variables, self-esteem and variables related to eating?

Table 3-12, 3-13 and 3-14 examine differences between those with and without eating disturbance on demographic variables, self-esteem and the four sub-categories of the CEDE respectively.

Table 3-12

Differences in demographics between those with and without Eating Disturbance

Demographics	EATING DISTURBANCE		Statistic	p-value
	Yes (n= 40)	No (n= 15)		
Mean Age SD, Range	14.2 1.93, 11.0-17.3	14.2 1.42, 11.6-16.4	t (53)= 0.002	1.00
Gender				
n (%) female	21 (52.5)	6 (40.0)	$\chi^2(1)= 0.68$	0.41
n (%) male	19 (47.5)	9 (60.0)		
AN BMI Range				
n (%) Desirable BMI range	18 (45.0)	7 (46.7)	$\chi^2(1)= 0.12$	0.91
n (%)	22 (55.0)	8 (53.3)		
Enteral Feeding				
n (%) yes	8 (20.0)	4 (26.7)	$\chi^2(1)= 0.28$	0.59
n (%) no	32 (80.0)	11 (73.3)		
Health Status				
n (%) mild	32 (80.0)	12 (80.0)	$\chi^2(1)= 0.00$	1.00
n (%) severe	8 (20.0)	3 (20.0)		
Pubertal Status				
n (%) pre puberty	19 (47.5)	8 (53.3)	$\chi^2(1)= 0.15$	0.70
n (%) post puberty	21 (52.5)	7 (46.7)		

Table 3-12 reveals that there were no significant differences between those with and without eating disturbance on any of the demographic variables. Of those with eating disturbance, just over half fell within the Desirable BMI range and were post-pubertal and the majority had mild levels of CF. Eight of the 12 participants who were undergoing enteral feeding had eating disturbance.

***Hypothesis 2b)** Eating disturbance will be evident in adolescents with CF irrespective of the severity of their condition.*

Table 3-12 reveals that there were no significant differences in health status between those with or without eating disturbance, which supports Hypothesis 2b.

***Hypothesis 3b)** The presence or absence of symptoms associated with eating disturbance will be related to differences in gender.*

Table 3-12 shows that there were no significant gender differences between those with or without eating disturbance, so Hypothesis 3b can be rejected.

Table 3-13

Differences in self-esteem between those with and without Eating Disturbance

EATING DISTURBANCE				
Mean Self-Esteem Scores	Yes (n= 40)	No (n= 15)	Statistic	p-value
Global Self-Esteem SD, Range	2.9 0.54, 1.7-4.0	3.4 0.50, 2.1-4.0	t (27)= 3.06	0.005+
Scholastic Performance SD, Range	2.7 0.63, 1.3-3.7	3.1 0.52, 2.2-4.0	t (30)= 2.55	0.016+
Social Acceptance SD, Range	3.1 0.69, 1.3-3.8	3.4 0.46, 2.8-4.0	t (38)= 2.00	0.052+
Athletic Competence SD, Range	2.4 0.80, 1.0-3.8	2.9 0.92, 1.0-4.0	t (22)= 1.90	0.071+
Physical Appearance SD, Range	2.5 0.63, 1.2-4.0	3.0 0.48, 2.2-4.0	t (33)= 3.30	0.002+
Behaviour SD, Range	3.1 0.60, 1.8- 4.0	3.2 0.74, 1.5-4.0	t (21)= 0.37	0.720+

† Equal Variances not assumed.

Hypothesis 4b) The presence or absence of symptoms associated with eating disturbance will be related to differences in self-esteem.

Table 3-13 reveals significant differences between those with and without eating disturbance on Global Self-Esteem, Scholastic Performance and Physical Appearance. The mean scores for those without eating disturbance on these three domains within self-esteem were higher than those obtained by participants with eating disturbance. These significant differences suggest that eating disturbance is related to differences in self-esteem and Hypothesis 4b is therefore supported.

Table 3-14

Differences in the Global CEDE sub-scale category scores between those with and without Eating Disturbance

EATING DISTURBANCE				
Sub-Scale Category Scores	Yes (n= 40)	No (n= 15)	Statistic	p-value
RESTRAINT SD, Range	0.26 0.75, 0-3.2	0	t (52)= 1.17	0.246
EATING CONCERN SD, Range	0.12 0.23, 0-0.8	0	t (52)= 1.84	0.071
SHAPE CONCERN SD, Range	0.50 0.79, 0-3.4	0.19 0.74, 0-0.29	t (52)= 2.18	0.034
WEIGHT CONCERN SD, Range	0.80 0.89, 0-4.6	0.19 0.33, 0-0.80	t (52)= 2.96	0.005

Table 3-14 reveals significant differences between those with and without eating disturbance on Shape Concern and Weight Concern only. Weight Concern then Shape Concern evidence the highest mean scores for participants with eating disturbance. Those without eating disturbance showed no evidence of Restraint or Eating Concerns but had Shape and Weight Concerns.

Further Investigations

Table 3-15 assesses the association of possible variables with eating disturbance. It is evident that four of the six Self-Esteem sub-scale domains are significantly negatively correlated with eating disturbance, whilst two of the four CEDE sub-scale categories are significantly positively correlated with eating disturbance. Whilst these variables are evidently associated with eating disturbance, the following analyses sought to examine whether they could independently predict eating disturbance in this sample.

Within the CEDE sub-scale categories there was a significant correlation between Shape Concern and eating disturbance. However three of the questions that are incorporated within Shape Concern, namely 'Shape Importance, Fear of Weight Gain and Feelings of Fatness' were utilised in the diagnosis of eating disturbance, which suggests an inevitable relationship between these two variables. Weight Concern incorporates one of the questions that was utilised in the diagnosis of eating disturbance. These two variables were therefore excluded from further analyses as they are evidently intrinsically part of eating disturbance.

A multiple regression revealed that five of the six Self-Esteem sub-scales were significantly related to each other ($F(5,49) = 14.6, p < 0.001$). More importantly the Multiple R was 0.8, which suggests Multicollinearity (Tabachnik & Fidell, 1996). Global Self-Esteem alone was therefore examined.

Although Eating Concern only approached significance, a Logistic Regression was utilised in order to determine whether the association between Global Self-Esteem and eating disturbance remained significant after controlling for Eating Concern. Overall the Logistic Regression was significant ($\chi^2(2) = 12.5, p = 0.002$). Global Self-Esteem was able to predict eating disturbance ($B = -1.71, Wald = 5.35, p = 0.02$), whilst Eating Concern was not ($B = 18.6, Wald = 0.72, p = 0.79$). Global Self-Esteem was therefore found to be a significant independent predictor of eating disturbance in this sample.

Table 3-15

Associations between eating disturbance, demographic variables, Self-Esteem and CEDE

Sub-Categories

EATING DISTURBANCE		
Variables	Statistic	p-value
DEMOGRAPHICS:		
Age	$r = 0.00$	1.000
Gender	$\chi^2(1) = 0.68$	0.419
AN BMI range	$\chi^2(1) = 0.01$	0.912
Enteral Feeding	$\chi^2(1) = 0.28$	0.594
Health Status	$\chi^2(1) = 0.00$	1.000
Pubertal Status	$\chi^2(1) = 0.15$	0.700
SELF-ESTEEM:		
Global Self-Esteem	$r = -0.37$	0.005
Scholastic Performance	$r = -0.31$	0.023
Social Acceptance	$r = -0.22$	0.100
Athletic Competence	$r = -0.27$	0.044
Physical Appearance	$r = -0.37$	0.005
Behaviour	$r = -0.06$	0.685
CEDE SUB-CATEGORIES:		
Restraint	$r = 0.16$	0.246
Eating Concern	$r = 0.25$	0.071
Shape Concern	$r = 0.29$	0.034
Weight Concern	$r = 0.38$	0.005

CHAPTER 4

DISCUSSION

Overview

This study aimed to survey the nature and prevalence of formal eating disorders and eating disturbance in adolescents with Cystic Fibrosis (CF). The main findings are summarised as follows:

Summary of Results

The Prevalence of Eating Disorders

1. None of the 55 participants met all of the criteria required for a diagnosis of either Anorexia Nervosa (AN) or Bulimia Nervosa (BN). However one male participant met the criteria for Eating Disorder Not Otherwise Specified (EDNOS).

The Prevalence of Eating Disturbance

Summary of Behaviours and Attitudes within the total sample

2. *Behaviour:* Disturbed behaviours were evident in up to 16% of the total sample, irrespective of Body Mass Index status (BMI) and included the use of exercising, the misuse of pancreatic enzyme medication and binge-eating behaviour for reasons to do with body shape or weight.

3. *Attitudes:* Disturbed attitudes ranging from fear of weight gain to feelings of fatness were evident in up to 16% of the total sample, despite the fact that none of the participants were over weight. Body shape and weight played significant roles in the self-evaluation of up to 53% of the total sample. Those within the Desirable BMI range

exhibited more disturbed behaviours than those whose weight fell within the AN BMI range, who exhibited disturbed attitudes.

The Nature of Eating Disturbance

4. *Restraint*: restraint from eating for reasons to do with body shape or weight was evident in the female sub-sample, within the AN BMI range but particularly within the Desirable BMI range. There was no significant difference in the restraint scores obtained by those with and without eating disturbance. *Eating Concern*: there was a trend towards increased concerns in female participants whose weight fell within the Desirable BMI range and in male participants whose weight fell within the AN BMI range. Differences in eating concern between those with and without eating disturbance approached significance. *Shape Concern*: shape concerns were evident in male and female participants irrespective of BMI status and those with eating disturbance obtained significantly higher mean Shape Concern scores than those without. There was evidence of body shape dissatisfaction and distorted body image. *Weight Concern*: weight concerns were also evident within male and female participants. The mean Weight Concern scores for those with eating disturbance was significantly higher than for those without.

5. There were no significant gender differences or differences in the health status of adolescents with or without eating disturbance, although global, scholastic performance and physical appearance self-esteem were negatively correlated with eating disturbance. Global self-esteem was found to be a significant, independent predictor of eating disturbance in this sample.

Discussion of Research Questions and Hypotheses

The research questions and hypotheses will be discussed in turn. Possible explanations for differences between this study and previous research studies will be discussed in relation to each research question and hypothesis and pertinent limitations of this study will be addressed. More general methodological limitations of this study will then be reviewed followed by the implications of the current findings for both future research and clinical practice.

Eating Disorders

Qu. 1a) What are the nature and prevalence of formal eating disorders in adolescents with CF?

A prevalence rate of 0% for AN and BN was found in this sample. However one male participant met the diagnostic criteria for EDNOS, which reflects a prevalence rate of atypical eating disorders (also known as ‘partial syndromes’), of 2% within this sample. Pumariega et al. (1986) found atypical eating disorders similar to AN in 3% and 9% of their male and female CF sample respectively, utilising the EAT-26 (Garner et al., 1982). Their sample ranged between 12 and 21 years. However they found evidence of low body weight and weight gain avoidance, which is not comparable with the findings within this study. Pearson et al. (1991, p.295) found, “clinically significant levels of AN” utilising DSM-III-R criteria (APA, 1987) in 10 out of 61 8-15 year-olds with CF, which reflects a prevalence rate of 16.4% within their sample. Further comparisons cannot be made due to the lack of information provided. In summary, a lower rate of formal eating disorders was found within this study in comparison to previous studies.

The differences between the studies may reflect differences in the participants recruited. The participants within the present study were aged between 11 and 17 years. Whilst formal eating disorders have been documented in individuals as young as eight years of age (Bryant-Waugh, 2000), Polivy and Herman (2002) note that individuals are most at risk of developing an eating disorder between the ages of 15 and 21 years. The mean age of participants within this study was 14.2 years and only approximately 50% of participants had reached puberty (which has been documented as a catalyst for the development of eating disorders in the general adolescent population, due to an increase in adipose tissue and consequently body fat (Sands et al., 1996)). This suggests that this sample may have been less likely to develop a formal eating disorder to date. Perhaps the greater prevalence of eating disturbance in comparison to the formal diagnoses of eating disorders within the present study reflects this. This will be examined below. A higher prevalence rate of formal eating disorders might therefore have been found in the present study if a greater number of *older* adolescents had participated.

It may be that the sample size of 28 males and 27 females was too small to detect formal eating disorders in this population. It is currently estimated that the prevalence rate within the general adolescent population is between 0.5 and 1% for AN and between 1 and 3% for BN (Carr, 1999). Further the male:female ratio for eating disorders has been estimated at 1:9 (Lask & Bryant-Waugh, 2000). Formal eating disorders may have been evident in a sample with a greater number of both male and female participants.

Formal eating disorders may not be evident due to the regular contact that CF patients have with their CF Centres. Weight, nutrition and appetite are all monitored routinely on

a three-monthly basis. However if any concerns are evident patients are monitored more regularly. Chronic weight concerns are treated through the use of enteral feeding, for example a naso-gastric tube or a gastrostomy. Consequently it may be that such regular contact with CF Centres prevents the development of formal eating disorder behaviours. Indeed, one female participant noted that she was weighed weekly by a Community Nurse. Further she commented, "I feel better now but I was happier with the way I looked when I was very skinny.... I would like to lose weight but not too much or I'll end up in here [hospital] again".

Taylor, Peveler, Hibbert and Fairburn (1992) acknowledge the shame and secrecy that commonly accompany eating problems. This is likely to be particularly pertinent in the CF population due to the increased risk that such difficulties pose to their health consequent to their condition. The low prevalence rate of eating disorders in this sample may be a result of participants' unwillingness to admit to frequent behaviours or intense concerns that they believe would be considered to be socially unacceptable consequent to their CF.

The differences between the studies may also reflect differences in the instruments utilised to detect eating disorders. The authors of the CEDE note that it is a particularly rigorous tool (Bryant-Waugh, Personal Communication, 2001), and therefore eating disorders may have been more prevalent in this sample if other tools had been utilised, such as anonymous diagnostic tools, which do not require face-to-face contact.

The low prevalence rate of formal eating disorders may also be associated with a lack of

fit between symptoms of eating disorders in this sample and the symptoms required for a diagnosis within DSM-IV (APA, 1994). All classification systems to date have been developed in relation to adults and DSM-IV (APA, 1994) is no exception (DaCosta & Halmi, (1992). Difficulties in relation to its use with younger adolescents include the requirement of amenorrhea for at least three months, which clearly does not take account of pre-menarcheal females.

Within the general child and adolescent population, Bryant-Waugh and Lask (1995) point out that only 50% of referrals to specialist eating disorders clinics fit the diagnostic criteria for either AN or BN when the patient is aged 15 years or younger. Nicholls et al. (1999) found that more than 50% of 226 children aged between 7 and 16 years either could not be classified or were diagnosed with EDNOS. One of their main findings was that many of their sample did not have an intense fear of fatness. This is comparable with the findings of the present study as none of the sample had an intense fear of fatness and only 4% acknowledged concerns about fatness. This is particularly pertinent to the CF adolescent population where the nature of their illness renders it extremely difficult to become fat.

Despite the evident difficulties regarding the utilisation of adult-focused classification systems, they continue to be utilised within the child and adolescent population. Whilst alternative diagnostic criteria have been developed clinically specifically for children and adolescents (Bryant-Waugh and Kaminski, 1993; Lask and Bryant-Waugh, 1993), to date there are no appropriate norms so they are of limited use for research purposes at this time.

IN SUMMARY

Formal eating disorders are not prevalent within this sample. It may be that symptoms within the CF adolescent population do not fit the current diagnostic criteria or it may be that a Type 2 error has occurred regarding the prevalence of formal eating disorders within this sample.

Hypothesis 1a) Adolescents with eating disorders are more likely to experience symptoms related to Anorexia Nervosa such as restraint from eating than to experience symptoms related to Bulimia Nervosa such as bulimic episodes.

This could not be formally evaluated as only one participant was diagnosed with a formal eating disorder. However the nature of the atypical eating disorder that was diagnosed revealed symptoms consistent with AN. None of the participants revealed diagnostic levels of binge eating episodes and thus it may be that eating disorders in adolescents with CF are rarely associated with BN but further research is required to examine this in more detail.

Qu. 2a) How does the prevalence of eating disorders in this sample compare to the general adolescent population and the diabetic adolescent population?

There was a lower prevalence rate of formal eating disorders, including AN, BN and EDNOS in this sample in comparison to the general adolescent population. Possible reasons for this were discussed in the section describing the prevalence of eating disorders.

Within the Insulin Dependent Diabetes Mellitus (IDDM) population, patients are able to facilitate weight loss through the manipulation of treatments, for example withholding insulin. Powers, Malone, Coovert and Schulman (1990) found that formally diagnosed eating disorders were no higher amongst IDDM patients. However the induction of glycosuria (the result of omitting insulin), to lose weight has been found to occur in between 12 and 39% of female diabetic patients (Rodin, Craven, Littlefield, Murray & Daneman, 1991; Stancin, Link & Reuter, 1989). This reflects a much greater prevalence of medication misuse within the IDDM population than the prevalence rate of 2% reported within this CF sample.

The low prevalence rate of pancreatic enzyme misuse is likely to reflect the significant side-effects such as stomach cramps and diarrhoea that are commonly associated with not taking enzyme supplementation (MacDonald, 1996). Whilst the physical effects of withholding insulin can be extremely dangerous, Williams and Pickup (1999) suggest that reducing occasional doses of insulin or missing occasional injections are likely to lead to side-effects such as nausea, which are perhaps less adverse in the short-term than the immediate symptoms experienced by CF patients when enzymes are withheld. The results of this study suggest that pancreatic enzyme misuse to facilitate weight loss is not prevalent.

Qu. 3a) How do a group of adolescents with CF and eating disorders compare with a matched group from the same population with CF but without eating disorders on a range of variables including demographic variables, self-esteem and variables related to eating?

This could not be evaluated due to the low prevalence of formal eating disorders within this sample.

Hypothesis 3a) The presence or absence of symptoms associated with eating disorders will be related to differences in gender.

This could not be evaluated as only one participant was diagnosed with a formal eating disorder.

Hypothesis 4a) The presence or absence of symptoms associated with eating disorders will be related to differences in self-esteem.

This could not be evaluated as only one participant was diagnosed with a formal eating disorder.

Eating Disturbance

1b) What is the nature and prevalence of eating disturbance in adolescents with CF?

Whilst formal eating disorders were evident in 2% of this sample, disturbed behaviours related to eating were evident in up to 16% of this sample. Two female participants whose weight fell within the Desirable BMI range noted that they had misused laxatives and induced vomiting in the past in order to control their shape and weight, whilst one male participant had induced vomiting in the past for this reason. It might have felt 'safer' to admit to past behaviours than current behaviours but the comments of these participants suggest that adolescents with CF may experiment with compensatory behaviours on a more frequent basis than has been highlighted in the present study. 4-11% of the total sample showed disturbed attitudes related to eating including concerns about weight gain irrespective of BMI status, and feelings of fatness in participants whose weight fell within the Desirable BMI range. Body shape and weight appeared to play a significant role in self-evaluation. Between 24% and 53% expressed this view. This has been documented separately as Bryant-Waugh (personal communication 2001), describes this as common within the adolescent population. Whilst it may be common, it still reflects disturbance and was therefore included within the analyses.

The prevalence rates of eating disturbance in the general adolescent population are not evident in published literature to date. However, the pattern of these findings is consistent with the clinical findings of Thompson and Smolak (2001), Nicholls et al. (2000), and Killen et al. (1994), all of whom suggest that eating disturbance is much more prevalent in the adolescent population than formal eating disorders. Indeed Killen

et al. (1994) estimate that eating disturbance is approximately four times more prevalent than formal eating disorders. In the present study behaviours related to eating disturbance are evident in up to 11% of the sample and attitudes related to eating disturbance are evident in over 50% of the sample, which suggests that eating disturbance appears to be prevalent within this sample. Further research studies, utilising the CEDE (Bryant-Waugh et al., 1996) are required to clarify whether or not these rates are higher than eating disturbance within the general adolescent population.

The Types of disturbed Behaviour

The type of behaviours utilised by male and female adolescents in this sample is comparable with the findings of other studies examining non-clinical adolescent populations. Within this sample more female than male participants were either attempting to maintain their weight at its current level or attempting to lose weight. This is reflected in the greater number of female participants who engaged in behaviours associated with restraint, and the consequently higher global restraint score obtained by female participants. A similar gender difference in type of behaviour utilised was found by Field et al. (1999). In a survey of 16,000 9-14 year-olds from the normal population they found that 44% and 19% of females and males respectively were attempting to lose weight.

Body shape importance was similar in male participants whose weight fell within the AN BMI range and the Desirable BMI range, whilst weight appeared to be important to more male participants whose weight fell within the AN BMI range than the Desirable BMI range. Further, a greater number of males who fell within the AN BMI range felt

dissatisfied that their shape was too small and their weight was too light. Drownowski and Yee (1987) suggest that the greater degree of perceived discrepancy between ideal and actual body shape is related to increased dissatisfaction with shape and weight. The findings of the present study may therefore reflect increased concerns about weight in male adolescents whose physiques are further removed from the muscular physique commonly portrayed as the ideal for males within Western society (Pope et al., 1999). The findings are comparable with the findings of male body dissatisfaction in the general population. Silberstein et al. (1988) found body dissatisfaction in males whose weight fell either below *or* above their ideal.

The majority of females whose weight fell within the AN BMI range did not feel dissatisfied that their weight was too low. This suggests that the attitudes of the female participants also appear to reflect the cultural ideal of slimness for females within the general adolescent population (Cash et al., 1986). Dissatisfaction that body shape and weight were too low was evident in a small minority of female participants within this sample. This is not comparable with the body image dissatisfaction literature within the general population. Silberstein et al. (1988) found that body dissatisfaction in females was uni-directional in that it occurred in females only when their current weight exceeded their ideal.

Good nutrition and consequently adequate weight is a major therapeutic target within CF Centres. CF patients have therefore been focussed upon their weight throughout their lives. The high prevalence rates of both body shape and weight importance within the whole sample and the existence of some dissatisfaction within the female AN BMI range

sub-sample may indicate that participants responded to these particular questions in a manner that reflected attitudes that they perceived to be expected of them consequent to their CF.

Hypothesis 1b) Adolescents with eating disturbance are more likely to experience symptoms related to Anorexia Nervosa such as restraint from eating than to experience symptoms related to Bulimia Nervosa such as bulimic episodes.

Only one female participant reported eating disturbance related to binge-eating. Although there was not a significant gender difference in the use of restraint nor was there a significant difference in the use of restraint in those with or without eating disturbance, behaviours associated with restraint were more evident within the female than the male sub-sample. This suggests that female adolescents with CF may be putting themselves in greater danger than male adolescents with CF by attempting to prevent weight gain through restraint rather than through the use of compensatory behaviours such as exercise. Restraint behaviours such as dieting are more common in the general female adolescent population than the male adolescent population (Field et al., 1999). Bell et al. (1985) note that the survival curves for females fall more rapidly than for males and that the fall for females is more rapid after ten years of age and parallels increasing weight retardation. This finding remains evident today (Dinwiddie, 2002). Whilst there was no significant difference in the Body Mass Index scores between males and females, any behaviours associated with restraint may be even more life-threatening than has been anticipated. Further research into restraining behaviours in the CF adolescent population is thus required.

Compensatory behaviours such as the use of exercise for reasons to do with body shape and weight were also evident in this sample. Exercise is encouraged within the CF population as it facilitates physiotherapy and consequently aids the respiratory management of the condition (Prasad et al., 2000). In recent years it has been suggested that exercise is a risk factor in the development and maintenance of eating disorders (Andersen, 1999; Sundogt-Borgen & Skarderud, 1999) but that this association depends upon the reasons behind exercising (McDonald & Thompson, 1992). Exercising for reasons to do with body shape and weight was evident within this sample. Further, a high percentage of participants described exercising on a regular basis, above and beyond the school curriculum, to facilitate physiotherapy. It may be that encouraging increased levels of exercise puts individuals with CF at increased risk of developing either eating disturbance or eating disorders in the future.

IN SUMMARY

Behaviours associated with restraint and the use of compensatory behaviours such as exercise for reasons to do with body shape and weight appear more common in this sample than binge-eating behaviours. Consequently this hypothesis can be cautiously confirmed.

Qu. 2b) How does the prevalence of eating disturbance in this sample compare to the general adolescent population and the diabetic adolescent population?

In total 73% of this sample showed evidence of eating disturbance. This high percentage appears to reflect the significant importance that both male and female participants

placed upon body shape and weight. Indeed, body shape was felt to be of significant importance to the self-evaluation of 24% and 36% of participants within the Desirable BMI range and the AN BMI range respectively, whilst body weight was felt to be of significant importance to the self-evaluation of 29% and 53% respectively. These high prevalence rates might actually reflect the clinical focus upon body shape and weight. However of particular interest is that only a minority of participants placed CF within their lists of things that were important to them regarding their self-evaluation. If CF clinics influence body shape and weight importance one might expect them to also influence the importance of their underlying medical condition relating to self-evaluation. This might indicate that these high percentages are reliable indicators of the importance that was placed upon body shape and weight within this sample. If this is the case, the significant importance placed upon both body shape and weight appears to pose a particular concern for male and female adolescents with CF. Body shape and weight is under scrutiny throughout the lives of CF patients, which might make them increasingly critical of their bodies. It seems that CF adolescents have two sources of pressure to consistently review their body shape and weight, namely general socio-cultural pressures and clinical pressures associated specifically with CF.

Within this current sample 11% of participants felt fat and 4% feared weight gain in comparison to 40% in a general adolescent population of 3,129 9-16 year olds (Childress et al., 1993). It is likely that the lower figures within the present study reflect the difficulty that CF patients experience in putting on weight. Evidence of any concerns about weight gain in the CF population is particularly worrying in light of the potentially fatal implications of low weight.

An examination of the literature within the adolescent diabetic population reveals lower levels of eating disturbance than is evident within the present study. Affenito et al. (1997) found a prevalence rate of 14% in their sample of 90. Nielsen and Grethe-Molbak (1998) suggest that those with diabetes do not demonstrate any increase in eating disturbance from that of the general population. However, they comment that female diabetic patients in particular are fully aware of the ease with which they can lose weight by manipulating their insulin treatment, which makes medication misuse particularly tempting. They suggest that insulin misuse is thus the predominant clinical concern for diabetic patients.

Qu. 3b) How do a group of adolescents with CF and eating disturbance compare with a matched group from the same population with CF but without eating disturbance on a range of variables including demographic variables, self-esteem and variables related to eating?

No significant differences were found between those with eating disturbance and those without on age, gender, BMI status, health status or pubertal status. The non-significant age and gender differences between those with and without eating disturbance are likely to be associated with the preoccupation with food and weight that is required throughout the lives of all patients with CF as part of treatment, irrespective of age and gender. This may also help to clarify the non-significant difference in pubertal status. Good nutritional status and consequently a satisfactory BMI is related to health status, both of which are regularly monitored. It may be that those with eating disturbance would have had lower BMI's if they did not experience both parental and professional pressure to

gain weight.

Hypothesis 2b) Eating disturbance will be evident in adolescents with CF irrespective of the severity of their condition.

There was no significant difference in health status between those with and without eating disturbance and therefore Hypothesis 2b can be confirmed. Whilst health status is associated with adequate weight (Dalzell et al., 1992), this finding highlights the fact that other factors also influence health status. Such factors have not been taken into consideration within this study but include differing genetic mutations and dual diagnoses (Family Resource Centre, 1996). However it must be noted that 80% of this sample had 'mild' CF and consequently further research examining the prevalence of eating disturbance in a larger sample of those with 'moderate' and 'severe' CF is required before this hypothesis could be applied to differing disease states.

Hypothesis 3b) The presence or absence of symptoms associated with eating disturbance will be related to differences in gender.

There were no significant gender differences between those with or without eating disturbance. The presence or absence of symptoms associated with eating disturbance does not therefore appear to be related to differences in gender and Hypothesis 3b can therefore be rejected.

Hypothesis 4b) The presence or absence of symptoms associated with eating disturbance will be related to differences in self-esteem.

It is evident from the self-esteem scores obtained within this sample that participants did not appear to have any particular concerns regarding self-esteem. This is not comparable with studies by Sinnema et al. (1988) and Pearson et al. (1991) who found that their CF participants experienced low self-esteem. They also utilised questionnaire methodology. However the different results may be due to the wider age range of participants within their respective samples as self-esteem is known to change with age (Harter, 1990) but also health status deteriorates with age in CF, which may adversely effect self-esteem. The difference may therefore reflect the self-esteem of a younger CF population. It would be interesting to compare the self-esteem scores of older CF patients to see if this is the case.

Those without eating disturbance obtained higher mean scores for all of the six self-esteem sub-scales, although differences were significant in global self-esteem, scholastic performance and physical appearance only. Participants with eating disturbance therefore appear to have lower self-worth, lower perceptions of their scholastic competency and appear less satisfied with their looks and personal attractiveness than a group of CF participants without such disturbances. Further analyses revealed that Global self-esteem was able to predict eating disturbance independently and this is comparable with previous research studies. Neumark-Sztainer et al. (1996) found that lower levels of self-esteem was one of the strongest predictors of eating disturbance, whilst Gual et al. (2001) found a consistent association between low self-esteem and the

prevalence of eating disorders in a study of 2,862 12-21 year-old females. The clear association between self-esteem and eating disturbance in the present study as well as previous research studies fits with the views of Harter (1990) that satisfaction with one's physical appearance is likely to be one of the main contributing factors towards one's global self-esteem. The findings of the present study support Hypothesis 4b as the presence or absence of symptoms associated with eating disturbance does appear to be related to differences in self-esteem, particularly related to global self-worth, perceptions of scholastic competence and adequacy and the individual's views of his/her physical appearance.

Further Investigations

Significant differences were found between those with and without eating disturbance on two of the sub-scale categories of the CEDE, namely Shape Concern and Weight Concern. Both of these sub-scale categories incorporate questions that are also diagnostic criteria, but also examine shape and weight satisfaction, which facilitates clarification of why they correlate so highly with eating disturbance. However, in accordance with diagnostic criteria, eating disturbance was found to correlate with shape and weight concerns within this study.

The mean scores obtained within Eating Concern approached significance regarding eating disturbance. This might have been influenced by scores obtained on 'Preoccupation with Food'. Whilst positive scores on this question indicate concentration impairment consequent to preoccupation, a degree of preoccupation is likely to be inevitable due to the focus of nutrition within treatment for CF (MacDonald, 1996). The

non-significant difference related to 'Restraint' might indicate that those with eating disturbance are more likely to utilise compensatory behaviours such as exercise as restraint from eating is likely to be difficult consequent to high levels of both parental and professional interest and encouragement in their food intake.

IN SUMMARY

Whilst prevalence rates of eating disorders appear to be lower in this sample population than eating disorders within other populations, levels of eating disturbance appear to be higher than in other populations. This is of significant concern in light of the potentially fatal consequences associated with low weight in the CF population. Empirical evidence within the general population supports the notion of continuity between eating disturbance and the development of full-syndrome eating disorders in the future (Catterin & Thompson, 1994; Thompson & Smolak, 2001). Those adolescents with CF who do experience eating disturbance may therefore be at risk of developing formal eating disorders in the future. However the applicability of a continuum within the CF population has not been formally examined to date.

Limitations of the Present Study

Methodology:

Bryant-Waugh et al. (1996) recommend that participants complete food diaries and diaries of 'significant events' prior to their interview, which acts as a memory aid during the interview. In light of the significant amount that patients with CF are encouraged to eat, participants and their parents or legal guardians were reluctant to do this. Instead, time was spent at the beginning of each interview completing a diary of significant

events and questioning participants about their appetite over that time in order to facilitate their recollection of events and to orient them to the time span in question. Results are consequently likely to have been influenced by recall bias which may have influenced the accuracy and consequently the reliability of responses (Bryant-Waugh et al., 1996). The accuracy of results could have been maximised by gathering follow-up information from relatives and members of the CF Teams. However it was felt that this would reduce the confidentiality of the interview, which may have adversely affected agreement to participate and may have reduced the accuracy of responses further. Within the CEDE the semi-structured interview format and the standardised manner with which questions were asked should limit the tendencies for interviewer bias, but this possibility cannot be excluded.

The participants within this study were aware that a trainee clinical psychologist was conducting this research. They were also aware that, due to their age and for ethical reasons, any evident concerns would have to be reported to their lead clinician, with their full knowledge. It is possible that the low prevalence rates of formal eating disorders within this sample were a result of either non-participation or concerns about the implications of admitting to certain behaviours such as restraint from eating. Such behaviours are considered to be particularly dangerous within the CF population, and would consequently require consultation with the lead clinician. Further, a significant amount of clinical psychology input within CF centres focuses upon behavioural and systemic strategies to facilitate weight gain. This may have exacerbated concerns about providing reliable results. Despite this Godley, Tchanturia, MacLeod and Schmidt (2001) suggest that the style of interaction between a researcher and a patient is usually

respectful, empathic and neutral about the responses given which may facilitate realistic rather than socially desirable responses. Further, participants appeared responsive and willing to share their experiences during interviews.

The Measures utilised

The CEDE (Bryant-Waugh et al., 1996) has not been used with patients with CF before. However, Fairburn et al. (1991) utilised the EDE with a diabetic population. The clinical management of this population also focuses upon nutrition as part of treatment and diabetics may also misuse medication to facilitate weight loss. They questioned their participants about medication misuse but otherwise adhered to the EDE, ensuring that responses were related to shape and weight rather than diabetes. They noted that the EDE facilitated a thorough examination of the eating habits and eating disorder psychopathology of their sample. The use of the CEDE within the present study provided a rich data set about the eating behaviours and attitudes of this sample. However the CEDE appears to have several limitations regarding its use with this particular population. It was necessary to regularly remind participants to consider their responses in relation to their views about their shape and weight rather than in relation to their CF. Further the instrument takes approximately one hour to complete and the questions are worded in a similar manner rendering it repetitive. Whilst this was unproblematic within a research context, it may not be an appropriate screening tool for regular clinical use with this population. It seems that a briefer measure is required for screening purposes and the CEDE could be utilised as a more thorough assessment tool if concerns are evident.

Sample Size

The statistical power for this study was based upon data obtained by Fairburn et al. (1991), utilising the adult version of the Eating Disorders Examination (EDE) (Fairburn and Cooper, 1993), to examine the nature and prevalence of eating disorders in young adults with diabetes. To date the CEDE has been validated only (Bryant-Waugh et al., 1996). It is important to note that population prevalence rates cannot be estimated from a sample of this size. A more accurate estimate of the prevalence of formal eating disorders would have been obtained with a larger sample size and therefore future investigations would benefit from a larger sample size. Whilst acknowledging this, the sample size utilised within this study is relatively substantial when considered within the context of previous, similar research studies. Further, multi-centre collaboration over considerable recruitment times would have been required to increase the sample size.

Type 1 Error

In order to minimise Type 1 errors, the analyses carried out were restricted to the hypotheses presented, which were based upon previous research studies, with the exception of the further analyses described.

Generalisability of Results

Whilst there were no significant differences between the two CF centres on any of the demographic variables examined, the majority of the sample described their ethnic background as “White British/ UK”. This reflects the high prevalence of CF within the Caucasian population (Green, 1996). However the results of this study should not necessarily be generalised to adolescents with CF from other ethnic backgrounds without

further investigation. The majority of the sample had mild CF and in total only 22% were undergoing enteral feeding, which suggests that the results may not be indicative of a larger sample of those with more severe CF or a larger sample of those undergoing enteral feeding. Again further research is required before these results can be extrapolated. The current study assessed eating disorder symptomatology in 11-17 year-olds so caution should be applied to other age groups as the evident eating disturbance may be specific to these particular 11-17 year-olds.

Those adolescents from different cohorts may have different concerns about food, eating and body image consequent to the continuing improvement in treatments and thus life expectancy (Pearson et al., 1991). Social and cultural changes in the future may mean that behaviours and attitudes within this age group change over time.

Implications for Future Research

This study has acted as a provisional survey and has found evidence of eating disturbance in both male and female adolescents with CF. Their concerns may reflect common adolescent behaviours and attitudes but the life-threatening consequences and the threat of a developmental continuum between eating disturbance and formal eating disorders means that this is of significant clinical concern.

This study has revealed that eating disturbance is evident in this adolescent CF sample, even with the use of a rigorous diagnostic tool. Findings would benefit from research that examines risk factors for the development of such disturbances. Based upon the similarities in the attitudes of adolescents with CF with their non-CF peers, it is likely

that the plethora of risk factors that have been widely documented in the general population might also influence the emergence of eating disturbance in vulnerable adolescents with CF, for example personality factors and stressors such as bereavement (Gowers et al., 1996; Killen et al., 1994). The generalisability of findings as well as the exact prevalence of such disturbance would be assisted through the use of multi-site studies.

Research examining eating disorders suggests a developmental continuum from eating disturbance to formal eating disorders (Thompson & Smolak, 2001). The evident feeding problems in children with CF (Stark, 1996) and the evidence gained from this study of eating disturbance in adolescents with CF renders longitudinal research of significant value in examining what specific factors may place this population at risk. It would be interesting to interview the participants of this study when they become adults to examine whether or not such a continuum is applicable to this sample, particularly when they gain more independence from their parents and consequently have greater levels of control over what they eat.

Future research would benefit from comparing the views of participants with those from their wider system, including their parents and health professionals within the CF team to facilitate the validation of findings. It would be interesting to compare the findings of this study with findings from a study where anonymous measures were utilised. The findings of this study would be enriched by interviewing more adolescents with CF from different ethnic groups where applicable and also those with different severities of CF.

Whilst the CEDE has been validated (Bryant-Waugh et al., 1996) norms and the requisite prevalence rates of both formal eating disorders and eating disturbance following its use have yet to be published and only then can clear comparisons be made.

Implications for Clinical Practice

Eating disturbance was evident in both male and female participants irrespective of age, BMI-status and pubertal status. This is not comparable with the literature within the general adolescent population where females are estimated to be significantly more at risk of eating disorder symptomatology. Carr (1999) reports a ratio of 1:9, male: female. Eating disorders are more prevalent within post-pubertal adolescents in the general population (Lask & Bryant-Waugh, 2000), which also differs from the results of this study. The results of this study therefore suggest that eating disturbance is present prior to puberty. This fits with the findings of Maloney et al. (1989) who found concerns about body shape and weight in children as young as seven. This suggests that CF clinics should attempt to work systemically to facilitate healthy eating attitudes as well as behaviours in males and females patients with CF of all ages.

The non-significant difference in BMI status suggests that one cannot assume that someone with a low BMI status has eating disturbance any more than one can assume that someone with a high BMI status does not. Other issues such as appetite loss or affective conditions such as anxiety and/or depression (which may not be picked up adequately in CF centres), may influence BMI status and the need to undergo enteral feeding more than eating disturbance alone. Clinicians need to be aware of the impact of other issues upon eating so that appropriate interventions can be implemented. A

failure to do this is likely to result in a lack of improvement in eating. The assessment and formulation skills of the clinical psychologist appear particularly useful here.

Disturbed behaviours such as the use of exercise to influence shape or weight were evident within this sample. Clinicians must consider the reasons why adolescents exercise, rather than assuming that the main reason is to facilitate physiotherapy, if patients are involved in a lot of sport. It seems that exercise is one type of weight/shape control behaviour that could go unnoticed within the CF population.

Disturbed eating attitudes were particularly prevalent within this sample. It may be that there is less of an association between attitudes and behaviours in younger CF patients and more of an association as patients get older and gain more independence. The association between early childhood experiences and later attitudes and behaviours is the main tenet of Cognitive Behaviour Therapy (Beck, 1995). Consequently clinical psychologists could facilitate more adaptive attitudes and behaviours related to eating in patients with CF by working in a consultative manner with the other members of the multi-disciplinary team. This could lead to the use of different, less authoritarian approaches to the management of nutrition within this population. It seems that a clear assessment of individual attitudes towards eating, shape and weight might be a useful initial step in identifying those who may be at risk of eating disturbance.

The ability of global self-esteem to predict eating disturbance suggests that a self-esteem measure may be of clinical use in helping to identify patients who may be at risk of eating disturbance or other psychological/ psychiatric difficulties. Whilst the Harter-

Hoare Self-Esteem questionnaire can be used with older adolescents, its wording is more appropriate for younger adolescents and children. CF centres could therefore benefit from utilising a more age-appropriate self-esteem questionnaire as a screening tool.

Currently it seems that CF patients exist in a non-CF culture and a CF culture. The former emphasises thinness whilst the latter emphasises weight gain. How these two cultures are brought together so that adolescents with CF can exist comfortably remains an elusive issue, particularly due to the current segregation policy. This was implemented four years ago due to concerns relating to the cross-infection of particular bacterial strains between patients with CF. Consequently CF patients are discouraged from mixing which suggests that the more common non-CF ideals of thinness and muscularity that are held by their non-CF peers are likely to take precedence over the CF ideals of weight gain. Indeed many of the participants within this study compared themselves to their friends at school and were particularly interested to find out whether their views were like those of other participants within this study. The experience of being able to compare views and attitudes with other adolescents with the same health concerns might be of significant benefit. This could be achieved through non face-to-face contact such as the use of 'CF' internet chat rooms.

Conclusion

Whilst formal eating disorders were not prevalent within this study, the existence of eating disturbance is of significant concern due to the potentially fatal consequences related to low weight within this population. It is clear that CF adolescents may pay with their lives for trying to live up to the current cultural ideals concerning body shape and

weight. These findings highlight the need for the early identification and treatment of any disturbance within this population.

Research into eating disorders and eating disturbance is still in its infancy in comparison to other psychiatric conditions despite the potentially fatal implications, which are heightened in clinical populations such as the CF population (Neiderman, 2000). With continued interest, effort and dedication, our current knowledge will improve, resulting in the prevention of such disabling conditions that impact upon the lives of so many.

CHAPTER 5:

REFERENCES

References

- Abraham, S. & Llewellyn-Jones, D. (2001). *Eating Disorders: The Facts (5th Edition)*. Oxford Medical Publications.
- Affenito, S., Gackstrand, J., Welch, G., Lammi-Keefe, C., Rodriguez, N. & Adams, C. (1997). Subclinical and clinical eating disorders in IDDM negatively affect metabolic control. *Diabetes Care*, 20, 182-184.
- American Psychiatric Association (1980). *Diagnostic and Statistical Manual of the Mental Disorders (3rd Edition)*. Washington, DC: Author.
- American Psychiatric Association (1987). *Diagnostic and Statistical Manual of the Mental Disorders (3rd Edition: Revised)*. Washington, DC: Author.
- American Psychiatric Association (1994). *Diagnostic and Statistical Manual of the Mental Disorders (4th Edition)*. Washington, DC: Author.
- Andersen, A. (1999). Gender-related aspects of eating disorders: A guide to practice. *Journal of Gender-Specific Medicine*, 2, 47-54.
- Barker, C., Pistrang, N. & Elliot, R. (1994). *Research Methods in Clinical and Counselling Psychology*. John Wiley & Sons.

- Beck, J. (1995). *Cognitive Therapy: Basics and Beyond*. The Guilford Press.
- Bell, L., Durie, P. & Forstner, G. (1984). What do Children with Cystic Fibrosis Eat? *Journal of Pediatric Gastroenterology and Nutrition* (3) (Suppl), S137-S146.
- Berger, K. (1987). *The Developing Person through the Life Span*. (2nd Edition.). Worth Publishers, Inc.
- Bhadrinath, B. (1990). Anorexia Nervosa in adolescents of Asian extraction. *British Journal of Psychiatry*, 156, 565-568.
- Blyth, D., Simmons, R. & Zakin, D. (1985). Satisfaction with body image for early adolescent females: the impact of pubertal timing within different school environments. *Journal of Youth and Adolescence*, 14, 207-226.
- Bryant-Waugh, R. (1994). Anorexia Nervosa in boys. In: B. Dolan & I. Gitzinger (Eds.). *Why Women?: Gender issues and eating disorders*. London: Athlone Press.
- Bryant-Waugh, R. (2000). Overview of the Eating Disorders. In: B. Lask and R. Bryant-Waugh, (2000). *Anorexia Nervosa and Related Eating Disorders in Children and Adolescence*. 2nd Edition. Psychology Press.
- Bryant-Waugh, R. (2001). *CEDE Training Course*. 11th May 2001.

Bryant-Waugh, R. & Kaminski, Z. (1993). Eating Disorders in Children: An Overview.

In: B. Lask & R. Bryant-Waugh (Eds.). *Childhood onset anorexia nervosa and related eating disorders*. East Sussex, UK: Erlbaum.

Bryant-Waugh, R. & Lask, B. (1991). Anorexia nervosa in a group of Asian children living in Britain. *British Journal of Psychiatry*, 158, 229-233.

Bryant-Waugh, R. & Lask, B. (1995). Annotation: Eating disorders in children. *Journal of Child Psychology and Psychiatry*, 36, 191-202.

Bryant-Waugh, R., Cooper, P., Taylor, C. & Lask, B. (1996). The use of the Eating Disorder Examination with children: A pilot study. *International Journal of Eating Disorders*, 19, 391-497.

Button, E. (1990). Self-esteem in girls aged 11-12: Baseline findings from a planned prospective study of vulnerability to eating disorders. *Journal of Adolescence*, 13, 407-413.

Carr, A. (1999). *The Handbook of Child and Adolescent Clinical Psychology: A Contextual Approach*. Routledge: London, New York.

Cash, T., Winstead, B. & Janda, L. (1986). The Great American shake-up: Body image survey report. *Psychology Today*, 20 (2), 30-37.

Catterin, J. & Thompson, J. (1994). A three-year longitudinal study of body image, eating disturbance and general psychological functioning in adolescent females. *Eating Disorders: The Journal of Treatment and Prevention*, 2, 114-125.

Childress, A., Brewerton, T., Hodges, E. & Jarrell, M. (1993). The kids' eating disorder survey (KEDS): A study of middle school children. *Journal of the American Academy of Child and Adolescent Psychiatry*, 32, 843-850.

Clinical Standards Advisory Group. (1993). *Cystic Fibrosis: access to and availability of specialist services*. London: HMSO.

Coleman, J. & Hendry, L. (2000). *The Nature of Adolescence. 3rd Edition*. Adolescence and Society Series: Routledge.

Crisp, A., Callender, J., Halek, C. & Hsu, L. Callender, Halek & Hsu (1992). Long-term mortality in anorexia nervosa. *British Journal of Psychiatry*, 161, 104-107.

Christ, W., McDonnell, P., Beck, M., Gillespie, C., Barrett, P. & Matthews, J. (1994). Behaviour at mealtimes and nutritional intake in the young child with Cystic Fibrosis. *Developmental and Behavioural Pediatrics*, 15, 157-161.

Coleman, J. & Hendry, L. (2000). *The Nature of Adolescence. 3rd Edition*. Routledge: Adolescence and Society Series.

Cooper, Z. & Fairburn, C. (1987). The Eating Disorders Examination: A Semi-structured interview for the assessment of specific psychopathology of eating disorders. *International Journal of Eating Disorders*, 6 (1), 1-8.

Cooper, Z. & Goodyer, I. (1994). *The nature and prevalence of weight and shape concerns amongst young girls*. Proceeding of the Rome Conference on Eating Disorders.

Cooper, Z., Cooper, P. & Fairburn, C. (1989). The Validity of the Eating Disorder Examination and its sub-scales. *British Journal of Psychiatry*, 154, 807-812.

Corey, M., McLaughlin, F., Williams, M. & Levison, H. (1988). A comparison of survival, growth and pulmonary function in patients with Cystic Fibrosis in Boston and Toronto. *Journal of Clinical Epidemiology*, 41, 583-591.

Crisp, A., Callender, J., Halek, C. & Hsu, L. (1992). Long-term mortality in Anorexia Nervosa. *British Journal of Psychiatry*, 161, 104-107.

Cystic Fibrosis Trust. (2000). 11 London Road, Bromley, Kent, BR1 1BY.

DaCosta, M. & Halmi, K. (1992). Classifications of Anorexia Nervosa: Questions of subtypes. *International Journal of Eating Disorders*, 11, 305-313.

Davison, K., Markey, C. & Birch, L. (2000). Etiology of body dissatisfaction and weight concerns among 5-year-old girls. *Appetite*, 35, 143-151.

Dalzell, A., Shepherd, R., Dean, B., Cleghorn, G., Holt, T. & Francis, P. (1992). Nutritional Rehabilitation in Cystic Fibrosis: A five-year follow-up. *Journal of Paediatric Gastroenterological Nutrition*, 15, 141-145.

Doyle, J. & Bryant-Waugh, R. (2000). Epidemiology. In: B. Lask & R. Bryant-Waugh (Eds.). *Anorexia Nervosa and related eating disorders in childhood and adolescence (2nd Ed.)*. East Sussex, UK: Psychology Press.

Drewnowski, A. & Yee, D. (1987). Men and body image: Are males satisfied with their body weight? *Psychosomatic Medicine*, 49, 626-634.

Eiser, C., Bozhena, Z., Hiller, J., Havermans, T. & Billig, S. (1995). Routine Stresses in caring for a child with Cystic Fibrosis. *Journal of Psychosomatic Research*, 39 (5), 641-646.

Elborn, J., Shale, D. & Britton, J. (1991). Cystic Fibrosis: current survival and population estimates to the year 2000. *Thorax*, 46, 881-885.

Erikson, E. (1968). *Identity: Youth and Crisis*. New York NY. WWWW Norton.

Esmond, G. (2000). Cystic Fibrosis: Adolescent Care. *Nursing Standard*, 14 (52), 47-52).

Fairburn, C. & Beglin, S. (1990). Studies of the epidemiology of bulimia nervosa. *American Journal of Psychiatry*, 147, 401-408.

Fairburn, C. & Cooper, Z. (1993). The Eating Disorder Examination (12th Ed.). In: C. Fairburn & G. Wilson (Eds.). *Binge eating: Nature, Assessment and Treatment*. p. 317-360. New York: Guilford Press.

Fairburn, G., Peveler, R., Davies, B., Mann, J. & Mayou, R. (1991). Eating disorders in young adults with insulin dependent diabetes mellitus: a controlled study. *British Medical Journal*, 303, 17-20.

Family Resource Centre. (1996). *Cystic Fibrosis*. Great Ormond Street Hospital for Children NHS Trust.

Fichter, M. & Daser, C. (1987). Symptomatology, psychosexual development and gender identity in 42 anorexic males. *Psychological Medicine*, 17, 409-418.

Field, A., Camargo, C., Taylor, C., Berkey, C., Frazier, L., Gillman, M. & Colditz, G. (1999). Overweight, weight concerns, and bulimic behaviours among girls and boys. *Journal of the American Academy of Adolescent Psychiatry*, 38, 754-760.

Fisher, M., Golden, N., Katzman, D., Kreipe, R., Rees, J., Schebendach, J., Sigman, G., Ammerman, S. & Hoberman, H. (1995). Eating disorders in adolescents: A background paper. *Journal of Adolescent Health, 16*, 286-294.

Flannery-Schroeder, E. & Chrisler, J. (1997). Body esteem, eating attitudes, and gender-role orientation in three age groups of children. *Current Psychology: Developmental, Learning, Personality, Social, 15*, 235-248.

Fosson, A., Knibbs, J. Bryant-Waugh, R. & Lask, B. (1987). Early onset anorexia nervosa. *Archives of Disease in Childhood, 62*, 114-118.

Frampton, I. (1996). Are overvalued ideas about weight and shape overvalued ideas in the diagnosis of eating disorders? Evidence from early onset anorexia nervosa. *Unpublished Research Dissertation*, University of Exeter, UK.

Fryer, S., Waller, G. & Kroese, B. (1997). Stress, coping and disturbed eating attitudes in teenage girls. *International Journal of Eating Disorders, 22*, 427-436.

Gardner, R., Sorter, R. & Friedman, B. (1997). Developmental changes in children's body images. *Journal of Social Behaviour and Personality, 12*, 1019-1036.

Garner, D. (1993). Defining socially and psychologically desirable body weights and the Psychological consequences of weight loss and weight gain. In: D. Allison & X. Pi Sunyer (Eds.). *Obesity treatment: Establishing goals, improving outcomes and reviewing the research agenda*. NATO ASI Series, New York NY, US: Plenum Press.

Garner, D. & Garfinkel, P. (1979). The Eating Attitudes Test: An index of the symptoms of anorexia nervosa. *Psychological Medicine*, 9, 273-279.

Garner, D. & Garfinkel, P. (1989). *Diagnostic Issues in Anorexia Nervosa and Bulimia Nervosa*. Bruner/Mazel editions. Monograph Series 2.

Garner, D., Olmsted, M. & Polivy, J. (1982). Development and validation of a multidimensional eating disorders inventory for anorexia nervosa and bulimia. *International Journal of Eating Disorders*, 2, 15-34.

Godley, J., Tchanturia, K., MacLeod, A. & Schmidt, U. (2001). Future-directed thinking in eating disorders. *British Journal of Clinical Psychology*, 40, 281-296.

Goldboom, D. (1988). Anorexia Nervosa and Cystic Fibrosis: A Case Report. *International Journal of Eating Disorders*, 7 (1), 433-437.

Gowers, S., Crisp, A., Joughin, N. & Bhat, A. (1991). Pre-menarcheal anorexia nervosa. *Journal of Child Psychology and Psychiatry*, 32, 515-524.

Gowers, S., North, C., Byram, V. & Weaver, A. (1996). Life event precipitants of adolescent anorexia nervosa. *Journal of Child Psychology and Psychiatry*, 37, 469-477.

Green, M. (1996). *Finding out about Cystic Fibrosis*. Cystic Fibrosis Trust. Research Support and Education. Cystic Fibrosis Trust, 11 London Road, Bromley, Kent BR1 1BY.

Gual, P., Perez-Gaspar, M., Martinez, G., Miguel, A., Lahortiga, F., de Irala-Estevez, J., Cervera, E. (2002). Self-esteem, personality and eating disorders: Baseline assessment of a prospective population-based cohort. *International Journal of Eating Disorders*, 31 (3), 261-273.

Halvarsson, K., Lunner, K., Westerberg, J., Anteson, F. and Sjoeden, P. (2002). *International Journal of Eating Disorders*, 31 (1), 32-42.

Hanning, R., Blimkie, C., Bar-Or, A., Lands, L., Moss, L. & Wilson, W. (1993). Relationships among nutritional status and skeletal and respiratory muscle function in Cystic Fibrosis: Does early dietary supplementation make a difference? *American Journal of Clinical Nutrition*, 57, 580-587.

Harter, S. (1985). *Manual for the Self-Perception Profile for Children*. Denver: University of Denver.

- Harter, S. (1989). Causes, correlates, and the functional role of global self-worth: a lifespan perspective. In: J. Kolligian & R. Sternberg (Eds.). *Perceptions of competence and incompetence across the life-span*. Yale University Press. New Haven, CT.
- Harter, S. (1990). Self and identity development. In: S. Feldman & G. Elder (Eds.). *At the threshold: the developing adolescent*. Harvard University Press. Cambridge, MA.
- Hawley, R. (1985). The outcome of anorexia nervosa in younger subjects. *British Journal of Psychiatry*, 146, 657-660.
- Herzog, D. & Bradburn, I. (1992). The nature of anorexia nervosa and bulimia nervosa in adolescents: In: P. Cooper & A. Stein (Eds). *Feeding problems and eating disorders in children and adolescents*. Chur, Switzerland: Harwood Academic.
- Higgs, J., Goodyer, I. & Birch, J. (1989). Anorexia nervosa and food avoidance emotional disorder. *Archives of Disease in Childhood*, 64, 346-351.
- Hill, A. & Bhatti, R. (1995). Body shape perception and dieting in preadolescent British Asian girls: Links with eating disorders. *International Journal of Eating Disorders*, 17, 175-183.

Hill, A. & Pallin, V. (1998). Dieting awareness and low self-worth: Related issues in 8-year old girls. *International Journal of Eating Disorders*, 24, 405-414.

Hill, A., Draper, E. & Stack, J. (1994). A weight on children's minds: Body shape dissatisfaction at 9-years-old. *International Journal of Obesity*, 18, 383-389.

Hoare, P., Elton, R., Greer, A. & Kerley, S. (1993). The Modification and Standardisation of the Harter Self-Esteem Questionnaire with Scottish School Children. *European Child and Adolescent psychiatry*, 2 (1), 19-33.

Hoek, H. (1993). Review of the Epidemiological Studies of Eating Disorders. *International Review of Psychiatry*, 5, 61-74.

Hoffman, L. & Halmi, K. (1993). Comorbidity and course of anorexia nervosa. *Child and Adolescent Clinics of North America*, 2, 129-144.

Hsu, L. (1990). *Eating Disorders*. New York: Guildford Press.

Hubbard, V. (1985). Nutritional considerations in Cystic Fibrosis. *Seminars in Respiratory Medicine*, 6, 308-313.

Jelalian, E., Mulvihill, M., Opiparim, L., Powers, S., Hovell M., Light, M., Harwood, I.,

Passero, M. & Stark, L. (1995). Inadequate oral intake in Cystic Fibrosis: The role of parent-child interactions. *Paper presented at the Florida Conference on Child Health care Psychology, Gainesville, Florida.*

Killen, J., Taylor, C., Hayward, C., Wilson, D., Haydel, K., Hammer, L., Simmonds, B.,

Robinson, T., Litt, I., Varady, A. & Kraemer, H. (1994). Pursuit of Thinness and Onset of Eating Disorder Symptoms in a Community Sample of Adolescent Girls: A Three-Year Prospective Analysis. *International Journal of Eating Disorders, 16* (3), 227-238.

Kreipe, R. & Uphoff, M. (1992). Treatment and outcome of adolescents with anorexia nervosa. *Adolescent Medicine, 3*, 519-540.

Lacey, H. & Dolan, B. (1988). Bulimia in British Blacks and Asians. *British Journal of Psychiatry, 152*, 73-79.

Lambert, M. & Cattani-Thompson, K. (1996). Current findings regarding the effectiveness of counselling: Implications for practice. *Journal of Counselling and Development, 74*, 601-608.

Lask, B. (2000). Eating disturbance in childhood and adolescence. *Current Paediatrics, 10*, 254-258.

Lask, B. & Bryant-Waugh, R. (1993). *Childhood Onset Anorexia Nervosa and Related Disorders*. Hove: Lawrence Erlbaum.

Lask, B. & Bryant-Waugh, R. (2000). *Anorexia Nervosa and Related Eating Disorders in Children and Adolescence*. 2nd Edition. Psychology Press.

Leff, J. & Vaughn, C. (1985). *Expressed emotion in families*. London: Guildford Press.

Levy, L., Durie, P., Pencharz, P. & Corey, M. (1986). Prognostic factors associated with patient survival during nutritional rehabilitation in malnourished children and adolescents with Cystic Fibrosis. *Pediatr Gastroenterol Nutr*, 5, 97-102.

MacDonald, A. (1996). Nutritional Management of Cystic Fibrosis. *Archives of Disease in Childhood*, 74, 81-87.

Maloney, M., McGuire, J., Daniels, S. & Specker, B. (1989). Dieting behaviour and eating attitudes in children. *Pediatrics*, 84, 482-487.

Marchi, M. & Cohen, P. (1990). Early childhood eating behaviours and adolescent eating disorders. *Journal of the American Academy of Child and Adolescent Psychiatry*, 29, 112-117.

McDonald, K. & Thompson, J.(1992). Eating disturbance, body image dissatisfaction and reasons for exercising: gender differences and correlational findings. *International Journal of Eating Disorders*, 11, 193-201.

Medical News. (1984). Progress continues against Cystic Fibrosis. *Journal of the American Medical Association*, 252, 2527.

Mellin, L., Irwin, C. & Scully, S. (1992). Prevalence of disordered eating in girls: A survey of middle-class children. *Journal of the American Dietetic Association*, 92, 851-853.

Mitchell, J., Hatsukami, D., Eckert, E. & Pyle, R. (1985). Eating Disorders Questionnaire. *Psychopharmacology Bulletin*, 21, 1025-1043.

Neiderman, M. (2000). Prognosis and Outcome. In: B. Lask & R. Bryant-Waugh (2000). *Anorexia nervosa and Related Eating Disorders in Childhood and Adolescence (2nd Edition)*. Psychology Press.

Neilsen, S. & Grethe-Molbak, A. (1998). Eating Disorder and Type 1 Diabetes: Overview and Summing-Up. *European Eating Disorders Review*, 6, 4-26.

Netemeyer, S. & Williamson, D. (2001). Assessment of Eating Disturbance in children and adolescents with eating disorders and obesity. In: J. Thompson & L. Smolak (Eds.). *Body Image, Eating Disorders and Obesity in Youth*. American Psychological Association. Washington, DC.

Neumark-Sztainer, D., Butler, R. & Palti, H. (1996). Personal and socioenvironmental predictors of disordered eating among adolescent females. *Journal of Nutrition Education, 28*, 195-201.

Nicholls, D., Chater, R. & Lask, B. (2000). Children into DSM don't go: A comparison of classification systems for eating disorders in childhood and early adolescence. *International Journal of Eating Disorders, 28*, 317-324.

Online Encyclopedia (2000). Microsoft R, Encarta R.

Parks, P. & Read, M. (1997). Adolescent male athletes: body image, diet and exercise. *Adolescence, 84*, 24-31.

Patton, G., Johnson-Sabine, E., Wood, K., Mann, A. & Wakeling, A. (1990). Abnormal eating attitudes in London schoolgirls- a prospective epidemiological study: Outcome at twelve month follow-up. *Psychological Medicine, 20*, 383-394.

Pearson, P., Pumariega, A., Seihleimer, D. & Bartholomew, K. (1988). Psychiatric symptomatology in younger and older cystic fibrosis patients. *Proceedings Annual Meeting, AACAP*, 4, 62.

Pearson, D., Pumariega, A. & Seilheimer, D. (1991). The development of psychiatric symptomatology in patients with Cystic Fibrosis. *Journal of the American Academy of Child and Adolescent Psychiatry*, 30, 290-297.

Pearson, P., Pumariega, A., Seilheimer, D. & Bartholomew, K. (1988). Psychiatric symptomatology in younger and older Cystic Fibrosis patients. *Proceedings Annual Meeting AACAP*, 4, 62.

Polivy, J. & Herman, C. (2002). Causes of Eating Disorders. *Annu. Rev. Psychol*, 53, 187-213

Pope, H., Olivardia, R., Gruber, A. & Borowiecki, J. (1999). Evolving ideals of male image as seen through action toys. *International Journal of Eating Disorders*, 26 (1), 65-72.

Powers, P. (19 97). Management of Patients with Comorbid Medical Conditions. In: Garner, D. & Garfinkel, P. (Eds.). *Handbook of treatment for Eating Disorders*. New York: The Guildford Press.

Powers, P., Malone, J., Coovert, D. & Schulman, R. (1990). Insulin-Dependent diabetes mellitus and eating disorders: A prevalence study. *Comprehensive Psychiatry*, 31, 205-210.

Prasad, S., Tannenbaum, E. & Mikelsons, C. (2000). Physiotherapy in Cystic Fibrosis. *Journal of the Royal Society of Medicine*, 38 (93), 27-35.

Pumariega, A. (1982). The adolescent with Cystic Fibrosis: Developmental issues. *Children's Health Care*, 11, 78-81.

Pumariega, A., Pearson, D. & Seilheimer, D. (1993). Family and Childhood Adjustment in Cystic Fibrosis. *Journal of Child and Family Studies*, 2 (2), 109-118.

Pumariega, A., Pursell, J., Spock, A. & Jones, J. (1986). Eating Disorders in Adolescents with Cystic Fibrosis. *Journal of the American Academy of Child Psychiatry*, 25, 269-275.

Raymond, N., Chang, P., Crow, S., Mitchell, J., Dieperink, B., Beck, M., Crosby, R., Clawson, C., Carlyle, W. & Warren, J. (2000). Eating disorders in patients with Cystic Fibrosis. *Journal of Adolescence*, 23 (3), 359-363.

Roberts, M. (1995). (1995). *Handbook of Pediatric Psychology, 2nd Edition*. The Guildford Press.))

Robins, L., Helzer, J., Cottler, L. & Goldring, E. (1989). *NIMH Diagnostic Interview Schedule, Version III Revised*. Washington, D.C.: National Institute of Mental Health.

Rodin, G., Craven, J., Littlefield, C., Murray, M. & Daneman, D. (1991). Eating disorders and intentional insulin under-treatment in adolescent females with diabetes. *Psychosomatics*, 32, 171-176.

Rosen, J., Vara, L., Wendt, B. & Leitenberg, H. (1990). Validity studies of the eating disorder examination. *International Journal of Eating Disorders*, 9, 519-528.

Sanders, M., Turner, K., Wall, C., Waugh, L. & Tully, L. (1997). Mealtime behaviour and parent-child interactions: A comparison of children with Cystic Fibrosis, children with feeding problems and non-clinic controls. *Journal of Pediatric Psychology*, 22, 881-900.

Sands, R., Tricker, J., Sherman, C., Armatas, C. & Maschette, W. (1996). Disordered Eating Patterns, Body Image, Self-Esteem, and Physical Activity in Preadolescent School Children. *International Journal of Eating Disorders*, 21 (2), 159-166.

Sawyer, S., Rosier, M., Phelan, P. & Bowes, G. (1995). The self-image of adolescents with Cystic Fibrosis. *Journal of Adolescent Health*, 16, 204-205.

Schmidt, U., Tiller, J. & Treasure, J. (1993). Setting the scene for eating disorders: childcare, classification and course of illness. *Psychological Medicine*, 23, 663-672.

Serdula, M., Collins, M., Williamson, D., Anda, R., Pamuk, E. & Byers, T. (1993). Weight control practices of U.S. adolescents and adults. *Annals of Internal Medicine*, 119, 667-661.

Shapiro, S., Newcomb, M. & Loeb, T. (1997). Fear of fat, disregulated-restrained eating, and body-esteem: Prevalence and gender differences among eight-to-ten-year-old children. *Journal of Clinical Child Psychology*, 26, 358-365.

Silberstein, L., Striegel-Moore, R., Timko, C. & Rodin, J. (1988). Behavioural and psychological implications of body dissatisfaction: Do men and women differ? *Sex Roles*, 19, 219-232.

Singer, L., Nofer, J., Benson-Szekely, L. & Brooks, L. (1991). Behavioural assessment and management of food refusal in children with Cystic Fibrosis. *Journal of Developmental and behavioural pediatrics*, 12, 115-120.

Sinnema, G., Bonarius, H., Van der Laag, D. (1988). The development of independence in adolescents with Cystic Fibrosis. *Journal of Adolescent Health Care*, 9, 53-66.

Smolak, L. & Levine, M. (2001). Toward an empirical basis for primary prevention of eating problems with elementary school children. *Eating Disorders: The Journal of Treatment and Prevention*, 2, 293-307.

Stancin, T., Link, D. & Reuter, J. (1989). Binge eating and purging in young women with IDDM. *Diabetes Care*, 12, 601-603.

Stark, L., Mulvihill, M., Powers, S., Jelalian, E., Keating, K., Creveling, S., Brynes-Collins, B., Miller, D., Harwood, I., Passero, M., Light, M. & Hovell, M. (1996). Behavioural intervention to improve calorie intake of children with cystic fibrosis: Treatment vs. wait-list controls. *Journal of Pediatric Gastroenterology and Nutrition*, 22, 240-253.

Stark, L., Mulvihill, M., Jelalian, E., Bowen, A., Power, S., Tao, S., Creveling, S., Passero, M., Harwood, I., Light, M., Lapey, A. & Melbourne, F. (1997). Descriptive analysis of eating behaviour in school-aged children with Cystic Fibrosis and healthy control children. *Pediatrics*, 99, 665-671.

Stein, A. & Fairburn, C. (1994). An infant with Cystic Fibrosis and a mother with an eating disorder: A difficult combination. *International Journal of Eating Disorders*, 16, 93-95.

Steiner, H., Rahimzadeh, P. & Lewiston, N. (1990). Psychopathology in Cystic Fibrosis and Anorexia Nervosa: A Controlled Comparison. *International Journal of Eating Disorders*, 9 (6), 675-683.

Stice, E., Killen, J., Hayward, C. & Taylor, C. (1998). Support for the continuity hypothesis of bulimic pathology. *Journal of Consulting and Clinical Psychology*, 66, 784-790.

Striegel-Moore, R., Schreiber, G., Lo, A., Crawford, P., Obarzanek, E. & Rodin, J. (2000). Eating Disorder Symptoms in a Cohort of 11 to 16-Year-Old Black and White Girls: The NHLBI Growth and Health Study. *International Journal of Eating Disorders*, 27, 49-66.

Sundogt-Borgen, J. & Skarderud, F. (1999). *Elite athletes and eating disorders*. Paper presented at the International Conference on eating Disorders, London, UK.

Super, M., Barnes, R., Greig, D. (2001). Failure to refer for testing for Cystic Fibrosis. *British Medical Journal*, 322, 310-311.

Tabachnik, B. & Fidell, L. (1996). *Using Multivariate Statistics*. 3rd Edition. Harper Collins, New York.

Taylor, A., Peveler, R., Hibbert, G. & Fairburn, C. (1992). Eating Disorders Among Women Receiving Treatment for an Alcohol Problem. *International Journal of Eating Disorders*, 14 (2), 147-151.

Thelen, M., Powell, A., Lawrence, C. & Kuhnert, M. (1992). Eating and body image concerns among children. *Journal of Clinical Child Psychology*, 21, 41-46.

Thomas, C., James, A. & Bachman, M. (2002). Eating attitudes in English secondary school students: Influences of ethnicity, gender, mood, and social class. *International Journal of Eating Disorders*, 31 (1), 92-96.

Thompson, J. & Smolak, L. (2001). *Body Image, Eating Disorders and Obesity in Youth*. American Psychological Association, Washington, DC.

Tiggemann, M. & Wilson-Barrett, E. (1998). Children's figure ratings: Relationship to self-esteem and negative stereotyping. *International Journal of Eating Disorders*, 23, 83-88.

Tomezsko, J., Stallings, V. & Scanlin, T. (1992). Dietary intake of healthy children with Cystic Fibrosis compared with normal control children. *Paediatrics*, 90, 547-553.

Wakeling, A. (1996). Epidemiology of Anorexia Nervosa. *Psychiatry Research*, 62, 3-9.

- Weltman, E., Stern, R., Doershuk, C., Moir, R., Palmer, K. & Jaffe, A. (1990). Weight and Menstrual Function in Patients with Eating Disorders and Cystic Fibrosis. *Pediatrics*, 85 (3), 282-287.
- Williams, G. & Pickup, J. (1999). *Handbook of Diabetes. 2nd Edition*. Blackwell Science Limited.
- Wilson, G. (1993). Assessment of binge eating. In: C. Fairburn & G. Wilson (Eds.). *Binge Eating: Nature, Assessment and Treatment*. New York: Guilford Press.
- Wolf, N. (1990). *The beauty myth*. London, Chatto and Windus.
- Wood, K., Becker, J. & Thompson, J. (1996). Body image dissatisfaction in preadolescent children. *Journal of Applied Developmental Psychology*, 17, 85-100.
- Wood, A., Waller, G., Miller, J. & Slade, P. (1992). The development of Eating Attitude Test scores in adolescence. *International Journal of Eating Disorders*, 11, 279-287.
- World Health Organisation (1992). *The ICD-10 Classification of Mental and Behavioural Disorders*. Geneva: World Health Organisation.

World Health Organisation (1996) *The ICD-10 Classification of Mental and Behavioural Disorders*. Geneva: World Health Organisation.

Yager, J., Andersen, A., Devlin, M., Mitchell, J., Powers, P. & Yates, A. (1993). American Psychiatric Association practice guidelines for eating disorders. *American Journal of Psychiatry*, 150, 207-228.

Zapletel, A. & Samenek, T. (1987). *Lung function in children and adolescents: methods and reference values*. Karger, Basel-Munchen.

Zellner, D., Harner, D., & Adler, R. (1989). Effects of eating abnormalities and gender on perceptions of desirable body-shape. *Journal of Abnormal Psychology*, 98, 93-96.

APPENDICES

APPENDIX 1:

The DSM-IV Criteria for Anorexia Nervosa (APA, 1994)

The Diagnostic Criteria for 307.1 Anorexia Nervosa

(DSM-IV, APA, 1994)

- A. *Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g. weight loss leading to maintenance of body weight less than 85% of that expected; or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected). **OR** BMI of $\leq 17.5\text{kg/ m}^2$.
- B. *Intense fear of gaining weight or becoming fat, even though under-weight.
- C. *Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.
- D. In postmenarcheal females, amenorrhea, i.e. the absence of at least three consecutive menstrual cycles. (A woman is considered to have amenorrhea if her periods occur only following hormone, e.g., estrogen, administration).

* Inclusion criteria for Males.

Specify type:

Restricting Type: during the current episode of Anorexia Nervosa, the person has not regularly engaged in binge-eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas).

Binge-Eating/Purging Type: during the current episode of Anorexia Nervosa, the person has regularly engaged in binge-eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas).

APPENDIX 2:

The DSM-IV Criteria for Bulimia Nervosa (APA, 1994)

The Diagnostic Criteria for 307.51 Bulimia Nervosa

(DSM-IV, APA, 1994)

- A. Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following:
- eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances.
 - a sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating).
- B. Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, enemas, or other medications; fasting; or excessive exercise.
- C. The binge eating and inappropriate compensatory behaviours both occur, on average, at least twice a week for 3 months.
- D. Self-evaluation is unduly influenced by body shape and weight.
- E. The disturbance does not occur exclusively during episodes of Anorexia Nervosa.

Specify type:

Purging Type: during the current episode of Bulimia Nervosa, the person has regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas.

Nonpurging Type: during the current episode of Bulimia Nervosa, the person has used other inappropriate compensatory behaviours, such as fasting or excessive exercise, but has not regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas.

APPENDIX 3:

The DSM-IV Criteria for Eating Disorder Not Otherwise Specified

(APA, 1994)

The Diagnostic Criteria for 307.50 Eating Disorder Not Otherwise Specified:

(DSM-IV, APA, 1994)

1. For females, all of the criteria for Anorexia Nervosa are met except that the individual has regular menses.
2. All of the criteria for Anorexia Nervosa are met except that, despite significant weight loss, the individual's current weight is in the normal range.
3. All of the criteria for Bulimia Nervosa are met except that the binge eating and inappropriate compensatory mechanisms occur at a frequency of less than twice a week or for a duration of less than 3 months.
4. The regular use of inappropriate compensatory behaviour by an individual of normal body weight after eating small amounts of food (e.g., self-induced vomiting after the consumption of two cookies).
5. Repeatedly chewing and spitting out, but not swallowing, large amounts of food.
6. Binge-eating disorder: recurrent episodes of binge eating in the absence of the regular use of inappropriate compensatory behaviours characteristic of Bulimia Nervosa.

APPENDIX 4:

Letters Confirming Ethical Approval

Institute of Child Health

and Great Ormond Street Hospital for Children NHS Trust

UNIVERSITY COLLEGE LONDON



The
child
first
and
always

23 April 2001

Dr M Bryon
Consultant Clinical Psychologist
Dept of Psychological Medicine
GOS

Dear Dr Bryon,

98BS23 Survey of the nature and prevalence of eating disorders in adolescents with cystic fibrosis

Thank you for your letter dated 30 March 2001 and apologies for the delay in responding. The Chairman of the Research Ethics Committee, Professor Mike Preece, has on behalf of the Committee approved the re-institution of the above project. Please note that ethics approval will expire on **24/04/2003**.

The decision will be ratified at the full Committee meeting that will take place on Wednesday 9 May 2001.

Yours sincerely

Orlagh Sheils
Administrator to the Research Ethics Committee
020 7905 2620
o.sheils@ich.ucl.ac.uk

cc: Ms J Shearër



THE QUEEN'S
ANNIVERSARY PRIZES
FOR HIGHER AND FURTHER EDUCATION

2000



Aneurin Bevan House
81 Commercial Road
London E1 1RD

Joanna Shearer
45C Fernhead Road
Maida Vale
London W9 3EX

Tel: 020 7655 6600
Fax: 020 7655 6666

Our ref: AR/SG/N/01/057

11th September 2001

Dear Ms Shearer

Re: N/01/057 - A Survey of the Nature and Prevalence of Eating Disorders in Adolescents with Cystic Fibrosis

Thank you for your letter of 24th July 2001 addressing the points of the Committee's earlier letter. I am happy to tell you that I am now able to approve this study on Chairman's action to be noted at future meeting of the Committee.

Please note the following conditions to the approval:

1. The Committee's approval is for the length of time specified in your application. If you expect your project to take longer to complete (i.e. collection of data), a letter from the principal investigator to the Chairman will be required to further extend the research. This will help the Committee to maintain comprehensive records.
2. Any changes to the protocol must be notified to the Committee. Such changes may not be implemented without the Committee or Chairman's approval.
3. The Committee should be notified immediately of any serious adverse events or if the study is terminated prematurely.
4. You are responsible for consulting with colleagues and/or other groups who may be involved or affected by the research, such as extra work for laboratories.
5. You must ensure that, where appropriate, nursing and other staff are made aware that research in progress on patients with whom they are concerned has been approved by the Committee.

6. The Committee should be sent one copy of any publication arising from your study, or a summary if there is to be no publication.

I should be grateful if you would inform all concerned with the study of the above decision.

Your application has been approved on the understanding that you comply with Good Clinical Practice and that all raw data is retained and available for inspection for 15 years.

Please quote the above study number in any future related correspondence.

Yours sincerely

A handwritten signature in black ink, appearing to read 'R. Smith', written over a faint circular stamp.

RICHARD SMITH

Vice Chair

ELCHA Research Ethics Committee

APPENDIX 5:

**Extracts from Ethics Application Forms noting that information would be
obtained for non-participants**

THE GOS/ICH RESEARCH ETHICS COMMITTEE

APPLICATION FORM Part 2

- Comparison of the means and standard deviations of scores on the Child Eating Disorder Examination with normative data and clinical groups for children of the same age. (This data is already published in the field of eating disorders).
- Overall rates of eating disorders found will be compared with published epidemiological data on incidence of eating disorder in other populations.
- Within-group analysis of a heterogeneous sample - those with an eating disorder will be compared with a group from the larger sample matched on appropriate variables on scores on the Harter self-esteem questionnaire, Paediatric Feeding Interview dimensions and parental emotional distress.
- Attempts will be made to co-ordinate this project with concurrent projects using the CEDE with a non-chronic illness population. The interviewers can then interchange for reliability checks.

b) What data will be collected on those who refuse consent?

It will be possible to obtain some demographic and health status data from the paediatric centres database on patients registered but who refuse to participate

c) If you took statistical advice on the overall design and analysis please state from whom.

Name

Institution

2.16 Disseminating the outcome.

a) How will you ensure that the results of the research are made available to the wider scientific / clinical community?

The aim will be to publish findings in a peer review journal and to present the findings as papers to international cystic fibrosis conferences.

b) Will the subjects be asked if they wish to be informed of the outcome of the project?

Yes A poster will be displayed in the CF clinics alerting to the availability of the findings and to contact the psychologist who will supply a summary information sheet.

If Yes, how will you ensure that their wishes are fulfilled?

No *If No, why not?*

**EAST LONDON & THE CITY HEALTH AUTHORITY
RESEARCH ETHICS COMMITTEE**

Application Form

A NEED FOR FURTHER RESEARCH:

The research documented above is limited due to the use of varied age ranges, self-report measures and the lack of objective psychiatric/psychological assessments. However they do reveal a vulnerability towards eating disorders in male and female adolescents with CF. The development of any eating disorder (starving, bingeing, purging or chaotic eating) in people with CF can have dangerous and occasionally fatal consequences, due to the malabsorption of nutrients and problems with sufficient weight gain and weight maintenance. Thus a more thorough understanding of the association between eating disorders and CF is vital.

Questions that will be addressed by this study are seen in the form of aims and include:

1. To describe the nature and prevalence of eating disorders in adolescents with CF aged from 11-17 attending CF paediatric centres.
2. To compare the prevalence of eating disorders with epidemiological data on prevalence rates of eating disorders in adolescent populations without other health problems.
3. To compare a group of adolescents with CF and eating disorders from the study with a matched group from the same population with CF but without eating disorders on variables such as self-esteem and health-status
4. To compare participants with those who chose not to participate on demographic and health status variables.

METHOD/Design:

All those aged between 11 and 17 years of age, with diagnosed CF who are registered on the CF database will be invited to participate. Males and Females will be included. All will complete the Harter/Hoare Self-Esteem Questionnaire (Hoare et al., 1993) and the Children's Eating Disorders Examination (Bryant-Waugh et al., 1996). The latter is a semi-structured interview, which elicits specific psychopathological features of eating disorders and has been utilised extensively within eating disorders research.

DURATION OF STUDY:

The study will commence in May 2001. It will end no later than May 2002.

JUSTIFICATION OF SAMPLE SIZE:

Results of a power analysis reveal that a sample size of 25 participants is required from The Royal London Hospital.

OTHER CENTRES:

A further sample of 25 will be obtained from Great Ormond Street Hospital.

APPENDIX 6:

Invitation to Participate: Participants

Invitation to Participate in a Research Project:

Dear Potential Participant,

We are inviting you to take part in a research study, which we think may be important. The research forms part of the researchers Doctoral Degree in Clinical Psychology. The information that follows tells you about it. It is important that you understand what is in this leaflet. It says what will happen if you take part and what the risks might be. Try to make sure you know what will happen to you if you decide to take part. Whether or not you do take part is up to you and one of your parents or your legal guardian. Please ask any questions you want to about the research and we will try our best to answer them.

- **Why have you been chosen to take part in the research?**

You have been asked to take part in this study because you are between 11 and 17 years old and you have Cystic Fibrosis.

- **What is the study about?**

The study wants to see what people your age with Cystic Fibrosis think about food, eating and what they look like.

- **What will I have to do?**

You will be asked to take part in an interview, where you will be asked about your eating and what you think about the way you look. You will also be asked to fill out a brief questionnaire called 'What I am Like'.

- **How long will it take?**

You will need to be seen once for no longer than 60 minutes by a female Trainee Clinical Psychologist.

- **What will I get out of taking part?**

By taking part in this study, you will be helping us to learn more about how people with Cystic Fibrosis feel about themselves and what they think about how they look. If you wanted to talk to someone more about this afterwards, we could help to sort that out for you.

- **Will I have to come back to hospital more than I normally do if I take part in the study?**

No. If you agree to take part, you could be seen before or after one of your Clinic appointments.

- **Could taking part in this study upset me in any way?**

The interview has never been known to upset people, but you can stop at any time and a Clinical Psychologist will be there if you want to talk to someone about it.

- **Are there any reasons why I should not take part in the study?**

We are looking for people between the age of 11 and 17 who have been diagnosed with Cystic Fibrosis and who can speak English well enough to understand the questions.

- **How will confidentiality be protected?**

The interview will be taped so that the researcher can make sure that nothing has been missed during the interview. The tape and all of the information gained will be treated like your medical records so will remain confidential. This is one of the agreements of the Consent form that you and your Parent/Legal Guardian will be asked to sign before the interview takes place. Once the research has finished the tape will be destroyed. If the researcher has any concerns after the interview, she will discuss it with you before talking to your Consultant.

- If you would like to talk to someone about the study before making a decision, please contact:

Lead Consultant,
Address

Or:

Joanna Shearer,
Trainee Clinical Psychologist,
Address

Tel:

Tel:

If you are worried about anything then you can call either (*Lead Consultant*) or Joanna Shearer. You do not have to join the study. You can decide not to be in this study or to drop out at any time. If you decide not to be in the study, or drop out, your ordinary medical care will not be effected.

We will take every care in the course of this study. If through our negligence any harm to you results, you will be compensated. However, a claim may have to be pursued through legal action. Even if the harm is not the Trust's fault your claim will be considered sympathetically. If you are not happy with any proposed compensation you may have to pursue your claim through legal action.

Yours Sincerely,

**Joanna Shearer
(Trainee Clinical Psychologist)**

APPENDIX 7:

Invitation for Child to Participate: Parents/ Legal Guardians

Invitation to Participate in a Research Project:

Dear Parent/Legal Guardian,

We invite your son/daughter to take part in a research study, which we think may be important. The research forms part of the researchers Doctoral Degree in Clinical Psychology. The information that follows tells you about it. It is important that you understand what is in this leaflet. It says what will happen if s/he takes part and what the risks might be. Try to make sure you know what will happen to him/her if you decide to give consent that s/he can take part. Whether or not s/he does take part is entirely up to you and your son/daughter. Please ask any questions you want to about the research and we will try our best to answer them.

- **Why has your son/daughter been identified as suitable to take part in the research?**

Your son/daughter has been asked to take part in this study because s/he is aged between 11 and 17 and has been diagnosed with Cystic Fibrosis.

- **What is the goal of the research?**

The goal of this research is to identify what attitudes adolescents with Cystic Fibrosis have about food and eating, and what kind of difficulties they might experience. This will help us to think about ways that we could provide help for such difficulties in the future.

- **What will be expected of your son/daughter?**

Your son/daughter will be asked to take part in an interview, where s/he will be asked about his/her eating and what s/he thinks about the way s/he looks. S/he will then be asked to complete a brief questionnaire entitled 'What I am Like'.

- **How long will your son/daughter be expected to participate?**

Your son/daughter will need to be seen once for no longer than 60 minutes. S/he will be interviewed by a female Trainee Clinical Psychologist.

- **What will your son/daughter gain from participating?**

By taking part in this study, your son/daughter will be helping us to learn more about how people with Cystic Fibrosis feel about themselves, what they think about their appearance, especially their weight and how they look. It might be interesting for him/her to discuss these issues and further support could be arranged if necessary.

- **Will your son/daughter have to come back to hospital more often than s/he normally does in order to take part in the study?**

If you and your son/daughter agree to take part, a researcher will contact both of you to arrange a convenient time when s/he could be seen. Perhaps s/he could attend before or after one of his/her Clinic Appointments.

- **Could participating in this study upset your son/daughter in any way?**

The interview has never been known to upset people. However, your son/daughter can stop at any time and speak to a qualified Clinical Psychologist who will be available if s/he wants to talk to someone about it.

- **Are there any reasons why your son/daughter should not take part in the study?**

We are looking for people between the age of 11 and 17 who have been diagnosed with Cystic Fibrosis and can speak English well enough to understand the questions.

- **How will confidentiality be protected?**

The interview will be taped so that the researcher can ensure that nothing has been missed during the interview. The tape and all of the information gained will be considered to be part of your son's/daughter's medical records and therefore will remain confidential. This is one of the agreements of the Consent form that you and your son/daughter will be asked to sign before the interview takes place. Once the research has been completed the tape will be destroyed. If any concerns become apparent following the interview, this will be discussed with your son/daughter and only then will information be passed on to his/her Consultant.

- **If you have any queries or concerns that you would like to talk to someone about, before making a decision, please contact:**

Lead Consultant,
Address

Or:

Joanna Shearer,
Trainee Clinical Psychologist,
Address

Tel:

Tel:

You will always be able to contact an investigator to discuss your concerns and/or to get help in an emergency from either (*Name of lead consultant*) or Joanna Shearer. Your son/daughter does not have to join the study. S/he is free to decide not to be in this study or to drop out at any time. If s/he decides not to be in the study, or drop out, his/her ordinary medical care will not be effected at all.

We will take every care in the course of this study. If through our negligence any harm to you or your son/daughter results, you will be compensated. However, a claim may have to be pursued through legal action. Even if the harm is not the Trust's fault your claim will be considered sympathetically. If you are not happy with any proposed compensation you may have to pursue your claim through legal action.

Yours Sincerely,

**Joanna Shearer
(Trainee Clinical Psychologist)**

APPENDIX 8:

Participation Form

PARTICIPATION FORM:

Please complete the form below and then send it back in the stamped, addressed envelope provided:

In BLOCK Capitals:

**NAME
OF PARENT/LEGAL GUARDIAN:.....**

**NAME
OF POTENTIAL PARTICIPANT:.....**

Please delete as appropriate:

Parent/ Legal Guardian:

I do / do not agree for my son/daughter to take part in the study.

SIGNATURE:

Potential Participant:

I do / do not agree to take part in the study.

SIGNATURE:

CONTACT DAYTIME TELEPHONE NUMBER:

Please provide alternative contact details if necessary:

Please provide convenient times for us to contact you:

APPENDIX 9:

Great Ormond Street Hospital Assent and Consent Forms

Great Ormond Street Hospital for Children NHS Trust and Institute of Child Health Research Ethics Committee

Assent Form for CHILDREN Participating in Research Studies

Title: A study exploring issues about food, eating and self image in adolescents with Cystic Fibrosis

NOTES FOR CHILDREN

1. You have been asked to take part in some research. The person organising that study must explain the project to you before you agree to take part.
2. Please ask the researcher any questions you like about this project, before you decide whether to join in.
3. If you decide, now or at any other time, that you do not wish to be involved in the research project, just tell us and we will stop the research. If you are a patient your treatment will carry on as it would normally.
4. You will be given an information sheet which describes the research. This information is for you to keep and refer to at any time. *Please read it carefully.*
5. If you have any complaints about the research project, discuss them with the researcher. If the problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee, by post via The Research and Development Office, Institute of Child Health, 30 Guilford Street, London WC1N 1EH or if urgent, by telephone on 020 7905 2620 and the committee administration will put you in contact with him.

ASSENT

I _____ agree that the Research Project named above has been explained to me to my satisfaction, and I agree to take part in this study.

I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

SIGNED	PRINTED	DATE
-----	-----	-----

SIGNED (Researcher)	PRINTED	DATE
-----	-----	-----

Great Ormond Street Hospital for Children NHS Trust and Institute of
Child Health Research Ethics Committee

**Consent Form for PARENTS OR GUARDIANS
of Children Participating in Research Studies**

Title: A study exploring issues about food, eating and self image in adolescents with Cystic
Fibrosis

NOTES FOR PARENTS OR GUARDIANS

1. Your child has been asked to take part in a research study. The person organising that study is responsible for explaining the project to you before you give consent.
2. Please ask the researcher any questions you may have about this project, before you decide whether you wish to participate.
3. If you decide, now or at any other stage, that you do not wish your child to participate in the research project, that is entirely your right, and if your child is a patient it will not in any way prejudice any present or future treatment.
4. You will be given an information sheet which describes the research project. This information sheet is for you to keep and refer to. *Please read it carefully.*
5. If you have any complaints about the way in which this research project has been or is being conducted, please, in the first instance, discuss them with the researcher. If the problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee, by post via The Research and Development Office, Institute of Child Health, 30 Guilford Street, London WC1N 1EH or if urgent, by telephone on 020 7905 2620 and the committee administration will put you in contact with him.

CONSENT

I/We _____, being the parent(s)/guardian(s) of
_____ agree that the Research Project named above has been
explained to me to my/our satisfaction, and I/We give permission for our child to take part
in this study. I/We have read both the notes written above and the Information Sheet
provided, and understand what the research study involves.

SIGNED (Parent (s)/Guardian (s))	PRINTED	DATE
-----	-----	-----
SIGNED (Researcher)	PRINTED	DATE
-----	-----	-----

APPENDIX 10:

The Royal London Hospital Assent and Consent Forms

WRITTEN ASSENT FORM:

A study exploring issues about food, eating and self image in adolescents with Cystic Fibrosis:
REC Number:

Name of Participant: (Block Capitals):

Address:

- The study organisers have invited me to take part in this research.
- I understand what is in the leaflet about the research. I have a copy of the leaflet to keep.
- I have had the chance to talk and ask questions about the study.
- I know what my part will be in the study and I know how long it will take
- I know how the study may affect me and I have been told about possible risks.
- I understand that I should not actively take part in more than 1 research study at a time.
- I know that the local East London and The City Health Authority Research Ethics Committee has seen and agreed to this study.
- I understand that personal information is strictly confidential: I know the only people who may see information about my part in the study are the research team.
- I know that the researchers will not inform my general practitioner (GP) about my part in the study.
- I freely consent to be a subject in the study and no-one has put pressure on me.
- I know that I can stop taking part in the study at any time.
- I freely consent for my interview to be audio taped and am aware that this will be treated as part of my medical records and destroyed when the research has finished.
- I know if I do not take part, I will still be able to have my normal treatment.
- I know that if there are any problems, myself or my parent/legal guardian can contact:

Lead Clinician: Tel: **Bleep No./Ext.**

Participant's Signature:

Witness's Name:

Witness's Signature:

Date:

Cont'd/...

The following should be signed by the Clinician/Investigator responsible for obtaining consent

As the Clinician/Investigator responsible for this research or a designated deputy, I confirm that I have explained to the patient/volunteer named above the nature and purpose of the research to be undertaken.

Clinician's Name:

Clinician's Signature:

Date:

WRITTEN CONSENT FORM:

A study exploring issues about food, eating and self image in adolescents with Cystic Fibrosis:
REC Number:

Name of Parent/Legal Guardian of Participant: (Block Capitals):

Address:

- The study organisers have invited my son/ daughter to take part in this research.
- I understand what is in the leaflet about the research. I have a copy of the leaflet to keep.
- I have had the chance to talk and ask questions about the study.
- I know what my son's/ daughter's part will be in the study and I know how long it will take.
- I know how the study may affect my son/ daughter and I have been told about the possible risks.
- I understand that my son/ daughter should not **actively** take part in more than 1 research study at a time.
- I know that the local East London and The City Health Authority Research Ethics Committee has seen and agreed to this study.
- I understand that personal information is strictly confidential: I know the only people who may see information about my son's/ daughter's part in the study are the research team.
- I know that the researchers will not inform my son's/ daughter's general practitioner (GP) about his part in the study.
- I freely consent for my son /daughter to be a subject in the study and no-one has put pressure on me.
- I know that my son/ daughter can stop taking part in the study at any time.
- I freely consent for my son's/ daughter's interview to be audio taped and am aware that this will be treated as part of his/ her medical records and destroyed upon completion of the research.
- I know if my son/ daughter does not take part, s/he will still be able to have his normal treatment.
- I know that if there are any problems, myself or my son/ daughter can contact:

Lead Clinician: Tel.

Bleep No./Ext.

Participants parent/legal guardian's Signature

Witness's Name:

Witness's Signature:

Date:

Cont' d/...

The following should be signed by the Clinician/Investigator responsible for obtaining consent

As the Clinician/Investigator responsible for this research or a designated deputy, I confirm that I have explained to the patient/volunteer named above the nature and purpose of the research to be undertaken.

Clinician's Name:

Clinician's Signature:

Date:

APPENDIX 11:

Demographic and Health Status Form

Demographic & Health Status Form

ID:

DOB:

ETHNICITY:

HEIGHT:

percentile:

WEIGHT:

percentile:

BMI:

FEV1:

litres:

% predicted:

PANCREATIC STATUS:

Sufficient/ Insufficient

ENTERAL FEEDING:

No/ Gastrostomy / NG tube

APPENDIX 12:

Descriptions of each of the Harter/Hoare Self-Esteem Questionnaire sub-
scales (Hoare et al., 1993)

Descriptions of the Harter/Hoare Self-Esteem Questionnaire sub-scales

(Hoare et al., 1993)

Global Self-Esteem: This examines the extent to which the child likes himself/herself as a person.

Scholastic Performance: This examines the child's perception of his/her competence academically.

Social Acceptance: This examines the extent to which the child is accepted by peers and feels popular.

Athletic Competence: This taps the child's perceived competence in outdoor sports and games.

Physical Appearance: This taps the degree to which the child feels happy with the way s/he looks. It includes the child's general appearance but also whether s/he sees herself/himself as good looking.

Behaviour: This examines the extent to which the child believes s/he behaves appropriately and does what is expected of him/her.

APPENDIX 13:

The Harter/Hoare Self-Esteem Questionnaire (Hoare et al., 1993)

WHAT I AM LIKE

Name _____ Age _____ Birthday _____ Class _____
 Boy or Girl (Please Circle) _____ Day _____ Month _____
 Child number _____

SAMPLE SENTENCE

	Really True for me	Sort of True for me		BUT		Sort of True for me	Really True for me
(a)	<input type="checkbox"/>	<input type="checkbox"/>	Some kids would rather play outside in their spare time		Other kids would rather watch T.V.	<input type="checkbox"/>	<input type="checkbox"/>

1.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids feel they are very good at their school work	BUT	Other kids worry about whether they can do their school work	<input type="checkbox"/>	<input type="checkbox"/>
2.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids find it hard to make friends	BUT	Other kids find it's pretty easy to make friends	<input type="checkbox"/>	<input type="checkbox"/>
3.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids do very well at all kinds of sports	BUT	Other kids don't feel they are good when it comes to sports	<input type="checkbox"/>	<input type="checkbox"/>
4.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are happy with the way they look	BUT	Other kids are not happy with the way they look	<input type="checkbox"/>	<input type="checkbox"/>
5.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids often do not like the way they behave	BUT	Other kids usually like the way they behave	<input type="checkbox"/>	<input type="checkbox"/>
6.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are often unhappy with themselves	BUT	Other kids are pretty pleased with themselves	<input type="checkbox"/>	<input type="checkbox"/>
7.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids feel they are just as clever as other kids	BUT	Other kids aren't so sure and wonder if they are as clever	<input type="checkbox"/>	<input type="checkbox"/>
8.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids have a lot of friends	BUT	Other kids don't have very many friends	<input type="checkbox"/>	<input type="checkbox"/>

	Really True for me	Sort of True for me		Sort of True for me	Really True for me		
9.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids wish they could be a lot better at sports	BUT	Other kids feel they are good enough at sports	<input type="checkbox"/>	<input type="checkbox"/>
10.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are happy with their height or weight	BUT	Other kids wish their height or weight was different	<input type="checkbox"/>	<input type="checkbox"/>
11.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids usually do the right thing	BUT	Other kids often don't do the right thing	<input type="checkbox"/>	<input type="checkbox"/>
12.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids don't like the way they are leading their life	BUT	Other kids do like the way they are leading their life	<input type="checkbox"/>	<input type="checkbox"/>
13.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are pretty slow in finishing their school work	BUT	Other kids can do their school work quickly	<input type="checkbox"/>	<input type="checkbox"/>
14.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids would like to have a lot more friends	BUT	Other kids have as many friends as they want	<input type="checkbox"/>	<input type="checkbox"/>
15.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids think they could do well at any new sport	BUT	Other kids are afraid they do not do well at new sports	<input type="checkbox"/>	<input type="checkbox"/>
16.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids wish their body was different	BUT	Other kids like their body the way it is	<input type="checkbox"/>	<input type="checkbox"/>
17.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids usually behave the way they know they're supposed to	BUT	Other kids often don't behave the way they're supposed to	<input type="checkbox"/>	<input type="checkbox"/>
18.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are happy with themselves as a person	BUT	Other kids are often not happy with themselves	<input type="checkbox"/>	<input type="checkbox"/>
19.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids often forget what they learn	BUT	Other kids can remember things easily	<input type="checkbox"/>	<input type="checkbox"/>
20.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are always doing things with a lot of kids	BUT	Other kids usually do things by themselves	<input type="checkbox"/>	<input type="checkbox"/>

	Really True for me	Sort of True for me			Sort of True for me	Really True for me	
21.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids feel they are better at sports than their friends	BUT	Other kids don't feel they can play as well	<input type="checkbox"/>	<input type="checkbox"/>
22.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids wish they looked different	BUT	Other kids like the way they look	<input type="checkbox"/>	<input type="checkbox"/>
23.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids usually get in trouble because of things they do	BUT	Other kids don't do things that get them into trouble	<input type="checkbox"/>	<input type="checkbox"/>
24.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids like the kind of person they are	BUT	Other kids often wish they were someone else	<input type="checkbox"/>	<input type="checkbox"/>
25.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids do very well at their classwork	BUT	Other kids don't do very well at their classwork	<input type="checkbox"/>	<input type="checkbox"/>
26.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids wish more people their own age liked them	BUT	Other kids feel that most people their own age do like them	<input type="checkbox"/>	<input type="checkbox"/>
27.	<input type="checkbox"/>	<input type="checkbox"/>	In games and sports some kids usually watch instead of play	BUT	Other kids usually play rather than just watch	<input type="checkbox"/>	<input type="checkbox"/>
28.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids wish something about their face or hair was different	BUT	Other kids like their face and hair the way they are	<input type="checkbox"/>	<input type="checkbox"/>
29.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids do things they know they shouldn't do	BUT	Other kids hardly ever do things they know they shouldn't do	<input type="checkbox"/>	<input type="checkbox"/>
30.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are very happy being the way they are	BUT	Other kids wish they were different	<input type="checkbox"/>	<input type="checkbox"/>
31.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids have trouble working out the answers in school	BUT	Other kids almost always can work out the answers	<input type="checkbox"/>	<input type="checkbox"/>
32.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are popular with others their own age	BUT	Other kids are not very popular	<input type="checkbox"/>	<input type="checkbox"/>

	Really True for me	Sort of True for me			Sort of True for me	Really True for me	
33.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids don't do well at new outdoor games	BUT	Other kids are good at new games right away	<input type="checkbox"/>	<input type="checkbox"/>
34.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids think that they are good looking	BUT	Other kids think that they are not very good looking	<input type="checkbox"/>	<input type="checkbox"/>
35.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids behave themselves very well	BUT	Other kids often find it hard to behave themselves	<input type="checkbox"/>	<input type="checkbox"/>
36.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are not happy with the way they do a lot of things	BUT	Other kids think the way they do things is fine	<input type="checkbox"/>	<input type="checkbox"/>

THANK YOU FOR YOUR HELP