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## Eating Attitudes and Behaviours in Males and Females with Cystic Fibrosis.

The Role of Body Image and Coping Styles.

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Thesis for the Degree of Doctorate in Clinical Psychology.

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I the undersigned confirm that the work I have presented as my thesis is entirely my own.

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Louise Melhuish	
Signed:	

#### **Abstract**

This thesis commences with a review of the literature on eating disorders and disturbed eating attitudes and behaviours (DEABs) in individuals with cystic fibrosis (CF). Certain physiological and psychological factors related to CF may contribute to the development of issues with food and eating. The major conclusions of the review support the notion of the presence of some DEABs in people with CF. However, it seems that the presence of diagnostic eating disorders is no higher than that found in the general population.

Limitations of the research are discussed and areas for future research are identified.

Following from this, the empirical paper investigated the relationships between eating behaviours and attitudes, coping styles and body image in individuals with CF. The findings suggest that females with CF present with higher rates of DEABs and males present with poorer body image. DEABs were found to be associated with poorer body image and unhelpful coping strategies. Clinicians should screen for DEABs at clinic

The results are considered in relation to prior research, and methodological limitations as well as clinical implications are discussed.

appointments to ensure that any difficulties do not impact on the health of the individuals.

#### **Contents**

## **Literature Review**

Abstract	3
Contents	4
List of Tables	10
Acknowledgements	11
Abstract	15
1.0 Introduction	17
1.1 Cystic Fibrosis	17
1.1.1. Poor Nutritional Status in Cystic Fibrosis	18
1.2 Diagnostic Eating Disorders	24
1.2.1. Anorexia Nervosa	25
1.2.2. Bulimia Nervosa	25
1.2.3. Eating Disorder Not Otherwise Specified (EDNOS)	28
1.3 Disturbed Eating Attitudes and Behaviours (DEABs)	28
1.4 Theories of Eating Disorders	30
1.4.1. Bio-psychosocial Theory	30
1.4.2. Starvation & Dieting Theories	31
1.4.3. Life Cycle & Transition Theories	32
1.4.4. Psychoanalytic/Psychodynamic	33
1.4.5. Cognitive Behavioural Model	33
1.4.6. Family Theories	34
1.4.7. Summary	36
1.5 Diabetes Mellitus & Other Chronic Health Conditions & DEABs	37
1.6 Physiological Risk Factors in Developing DEABs in CF	41
1.7 Psychosocial Risk Factors in Developing DEABs in CF	42
2.0 Method	45
2.1 Literature Search Strategy	45

2.2 Inclusion & Exclusion Criteria	45
3.0 Results	47
3.1 Diagnostic Eating Disorders	47
3.2 Disturbed Eating Attitudes and Behaviours (DEABs)	50
3.2.1. Children & Adolescents	51
3.2.2. Adults	56
4.0 Discussion	61
4.1 Methodological Considerations	61
4.2 Clinical Implications	63
4.3 Future Directions	65
5.0 Conclusion	67
References	69

#### **Contents**

## **Empirical Paper**

Abstract	91
1.0 Introduction	93
1.1 Overview	93
1.2 Cystic Fibrosis & Nutrition	93
1.3 Theoretical Overview	94
1.4 Disturbed Eating Attitudes and Behaviours & Cystic Fibrosis	95
1.5 Coping Styles & Cystic Fibrosis	97
1.6 Body Image & Cystic Fibrosis	98
1.7 Quality of Life & Cystic Fibrosis	101
1.8 Formulation of Current Study	103
1.9 Hypotheses	103
2.0 Method	105
2.1 Design	105
2.2 Setting	105
2.3 Sample	105
2.3.1. Inclusion & Exclusion Criteria	105
2.4 Sample Size	106
2.5 Recruitment	106
2.6 Participant Characteristics	107
2.7 Measures	108
2.7.1. Eating Attitudes Test	109
2.7.2. Cystic Fibrosis Eating Attitudes and Behaviours Questionnaire	110
2.7.3. Cystic Fibrosis Body Image Scale	111
2.7.4. Figure Rating Scale	111
2.7.5. Cystic Fibrosis Coping Scale	112
2.7.6. The Cystic Fibrosis Questionnaire	112
2.8 Procedure	113

2.9 Ethical Considerations	114
2.10 Statistical Analysis Strategy	114
3.0 Results	117
3.1 Clinical Variables	117
$3.1.1.  \text{FEV}_1  \&  \text{BMI}$	117
3.1.2. Age & BMI	118
3.1.3. Diabetes & FEV <sub>1</sub>	118
3.1.4. Pancreatic Insufficiency & BMI	118
3.2 Descriptive Statistics	119
3.3 Missing Data	121
3.4 Eating Attitudes & Behaviours	121
3.4.1. Correlations of the EAT & CFEAB	121
3.4.2. Significant Eating Difficulties	121
3.4.3. Eating Behaviours & Attitudes & Clinical Variables	122
3.5 Eating Attitudes and Behaviours in Males & Females	123
3.6 Body Image in Males & Females	124
3.6.1. Body Image Scale	124
3.6.2. Figure Rating Scale	125
3.7 Eating Attitudes & Behaviours & Coping Styles	126
3.7.1. Male & Female Eating Attitudes & Behaviours & Coping Styles	127
3.8 Eating Attitudes & Behaviours & Body Image	129
3.8.1. Eating Attitudes & Behaviours & the Body Image Scale	129
3.8.2. Moderated Effect of Gender	131
3.8.3 Eating Attitudes & Behaviours & the Figure Rating Scale	133
3.9 Eating Attitudes & Behaviours and Quality of Life	135
4.0 Discussion	137
4.1 Interpretation of Key Findings	137
4.2 Clinical Implications	141
4.3 Strengths & Limitations	144

#### EATING BEHAVIOUR AND ATTITUDES IN INDIVIDUALS WITH CYSTIC FIBROSIS

4.4 Directions for Future Research	148
5.0 Conclusion	151
References	153

## **Appendices**

Appendix A: Adult Invitation Letter	166
Appendix B: Parent Invitation Letter	167
Appendix C: Adult Information Sheet	168
Appendix D: Young Person Information Sheet	174
Appendix E: Parent/Legal Guardian Information Sheet	178
Appendix F: Demographics Form.	184
Appendix G: Cystic Fibrosis Eating Attitudes & Behaviours Questionnaire	186
Appendix H: Principal Component Analysis	187
Appendix I: Adult Consent Form	191
Appendix J: Young Person Assent Form	193
Appendix K: Parent/Legal Guardian Consent Form	195
Appendix L: NHS Favourable Opinion Letter	197
Appendix M: R&D Approval Letter	201

#### **List of Tables**

Table 1: Anorexia nervosa criteria	26
Table 2: Bulimia nervosa criteria.	27
Table 3: Descriptive statistics of the measures and subscales	119
Table 4: Correlations of eating behaviours and attitudes and clinical variables	122
Table 5: Descriptive statistics of the EAT and the CFEAB for males and females	123
Table 6: Descriptive statistics of the body image questionnaire and the FRS for males and	
females	125
Table 7: Descriptive statistics of the coping style questionnaire for males and females	
	128
Table 8: Regression to test the moderated effect of gender in eating behaviours and	
attitudes and body image	132
Table 9:One-tailed Spearman's correlation coefficient of the EAT and CFEAB and QoL	
	135
List of Figures	
Figure 1: Model of the aetiology of malnutrition in Cystic Fibrosis	22
Figure 2: Interaction of gender by body image total and the CFEAB	133
Figure 3: Scatterplot correlation of the CFEAB and the FRS difference	134

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## A Critical Review of Eating Disorders and Disturbed Eating Attitudes and Behaviours in Individuals with Cystic Fibrosis.

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#### **Abstract**

The review was conducted to examine disturbed eating attitudes and behaviours including diagnostic eating disorders in the context of cystic fibrosis (CF). Previous research has suggested a relationship between CF and disturbed eating attitudes and behaviours (DEABs). Certain physiological and psychological factors related to CF may contribute to the development of issues with food and eating. Therefore, a review of the literature on eating disorders and DEABs in children, adolescents and adults with CF is presented. Electronic databases were searched for potential papers relating to these issues. Twenty-six papers have been included in the review. The major conclusions of the review support the notion of the presence of some DEABs in people with CF. However, it seems that the presence of diagnostic eating disorders is no higher than that found in the general population. Clinicians should screen for DEABs at clinic appointments to ensure that any difficulties do not impact on the health of the individuals. Further clinical implications are explored and considerations for future research are also considered.

#### 1.0 Introduction

The review aims to explore the available research findings in relation to eating disorders and disturbed eating attitudes and behaviours (DEABs) in cystic fibrosis (CF). In order to orient the reader the introduction will provide an overview of CF, eating disorders in the general population and the theoretical conceptualisations of eating disorders. This will then be followed by a consideration of both physiological and psychosocial aspects that may offer insight into factors that may make individuals with CF more vulnerable to developing DEABs.

#### 1.1 Cystic Fibrosis

Cystic Fibrosis (CF) is the most common fatal hereditary disease in the Caucasian population (Boat, Welsh, Beaudet, 1989). There are currently over 8,500 people living in the United Kingdom with CF (Cystic Fibrosis Trust, 2009). Diagnosis is often made in infancy but is also made in early adulthood with the less severe forms or uncommon variants of the disease. Around one in 20 people in the Caucasian population are carriers of the faulty gene (Dodge et al. 1997) and in the UK there is an incidence rate of around 0.4 per 1000 new-borns (Dodge, Lewis, Stanton, & Wilsher, 2007).

CF is primarily a disease of exocrine glands, affecting sweat production, pancreatic secretions and mucus production in the lungs and sinuses (Hayes, Sheehan, Ulchaker &

Rebar, 1994). This results in accumulations of mucus and bacteriological colonisation in the lungs (Blair, Freeman & Cull, 1995).

Many individuals with CF experience recurrent lung infections, pancreatic insufficiency which leads to maldigestion and malabsorption of nutrients, and excessive losses of sweat electrolytes (Creveling, Light, Gardner & Greene, 1997; Dowsett, 1996; Hayes et al. 1994). Some of the symptoms experienced by individuals with CF include a chronic cough that produces thick mucus, weight loss, bowel problems and repeated or prolonged episodes of pneumonia (Canadian Cystic Fibrosis Foundation, 1996). Secondary consequences of the disease include CF- related diabetes and liver disease.

In the past two decades due to medical advances in treatment procedures predicted survival rates have improved significantly. The median predicted survival rate for individuals with CF in the UK in 2008 was 38.8 years (CF Trust, 2009). The trajectory of the illness and its severity vary by individual and despite technical advances in understanding the genetics and pathophysiology of CF, a curative treatment is not yet available (Sawyer et al. 2005). Therefore, the individuals with CF experience complex and time consuming daily treatments consisting of chest physiotherapy, inhalation therapy, pancreatic enzyme supplements and regular antibiotic treatments to manage the disease and prevent its progression.

#### 1.1.1. Poor Nutritional Status in Cystic Fibrosis.

Many individuals with CF display poor nutritional status and this is partly connected to some of the medical issues outlined previously. Pancreatic insufficiency is prevalent in 85-90% of individuals with CF (Borowitz, 1994) which leads to maldigestion and malabsorption of nutrients. Thus, individuals with CF are at high risk of malnutrition (Mahan & Escott-Stump, 2004). This can often contribute to difficulties in individuals meeting their nutritional needs and so dietary management and good nutritional status is essential in this population. Malabsorption can be clinically corrected with pancreatic enzyme replacements; maldigestion and malabsorption, however, continue to be a problem in most individuals with CF (Elborn & Bell, 1996).

Malnutrition is common in individuals with CF, mostly presenting as a low body weight and subnormal growth (Sinaasappel et al. 2002). Studies exploring the dietary intake of individuals with CF have reported a prevalence of malnutrition between 24% and 59% (Lai et al. 1998; Dray et al. 2004; Steinkamp & Weidemann, 2002).

Chronic malnutrition, significant weight loss and growth failure are common problems of patients with CF (Durie & Pencharz, 1992) and many individuals are therefore underweight for their age (Jelalian, Stark, Reynolds & Seifer, 1998). It has been reported that at least 21% of adults with CF have a body mass index (BMI) below 19 (CF Trust, 2009) which is categorised as underweight.

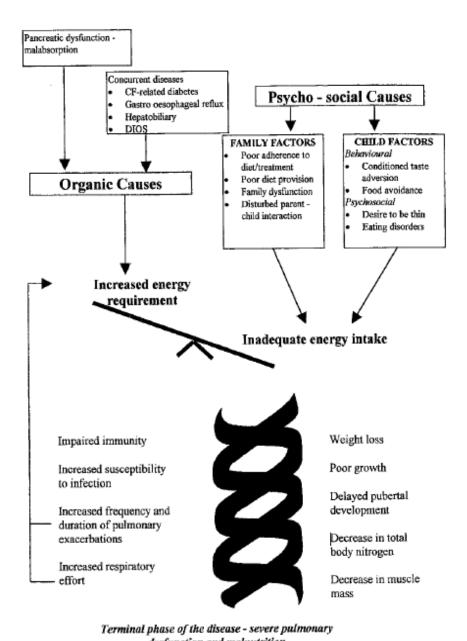
Poor nutritional status in CF has been associated with poor growth and delayed puberty (Dodge, 1992), reduced lung function in children and adults (Peterson, Jacobs Jr., & Milla, 2003; Steinkamp & Weiderman, 2002; Zemel, Jawad, Fitzsimmons & Stallings,

2000) and eventually a decreased survival rate (Beker, Russek-Cohen, & Fink, 2001; Corey, McLaughlan, Williams, & Levison, 1988; Sharma et al. 2001). Survival rates have been reported to be significantly lower in females (Australian Cystic Fibrosis Association, 1994; CCFF, 1996; Dodge et al. 1993), and although the reason for this remains unclear at present, Corey and Farewell (1996) suggest that this could partially be explained by lower weights in females with CF.

Dietary management is a significant part of treatment in the CF population and sometimes oral and enteral tube feedings may be necessary if individuals are unable to meet appropriate levels of nutrition. Corey et al.'s (1988) study highlighted the importance of nutrition in CF patients through comparing CF clinics. Two clinics in Toronto and Boston offered different nutritional advice and it was noticed that there was a significant improved prognosis in the Toronto CF population which encouraged a calorie-enriched diet with an intake of high fat content foods. A high-energy, high protein diet is therefore recommended to individuals with CF to compensate for the malabsorption (Dodge, 1992). Individuals with CF are recommended to adhere to diets of 120% to 150% of the recommended daily allowance of food intake in order to maintain the estimated energy requirements (Creveling et al. 1997). Intensive dietary management has been found to be beneficial in fighting infection and promoting survival in individuals with CF (Dowsett, 1996).

With media and educational messages regarding healthy diets and a preference for slimness individuals with CF may struggle to adhere to the high-fat and high-calorie dietary recommendations. Non-adherence to pancreatic enzyme supplements, nutritional supplements and diet recommendations may occur in order to achieve or maintain CF-induced slimness. Literature on treatment adherence indicates dietary recommendations are the least adhered to aspects of treatment in individuals with CF (Gudas, Koocher & Wypij, 1991; Schultz & Moser, 1992) despite their high importance.

It seems that many factors, both physiological and psychological are inter-related in the development of poor nutritional status in individuals with CF. Anthony, Paxon, Catto-Smith and Phelan (1999; Figure 1) have developed a model to illustrate many of the factors contributing to the malnutrition of individuals with CF.



dysfunction and malnutrition

**Figure 1**. *Model of the aetiology of malnutrition in CF (Anthony et al. 1999).* 

Malnutrition is a complicating factor in the disease process of CF and the model highlights both organic and psychosocial factors that may play a role. A variety of

organic causes including pancreatic insufficiency and the presence of other diseases, such as CF-related diabetes, reflux and heptobiliary disease (Gaskin, 1988; Pencharz & Durie, 1993) all contribute to increased energy requirements in people with CF.

Anthony et al. (1999) indicate that both familial and individual psychosocial factors may play a role in the malnutrition of individuals with CF. The model suggests that the system supporting the individual with CF may affect the extent to which CF treatments are adhered to. Most treatment is home-based and anecdotal evidence suggests that outcomes are worse for children whose family find it difficult to adhere to a daily treatment regime (Anthony et al. 1999). In studying the relationship between family functioning, coping behaviours and physiological function in children Patterson, McCubbin and Warwick (1990), Patterson, Budd, Goetz and Warwick (1993) and Patterson (1985) identified that coping strategies of families could be linked with physiological outcomes in children with CF.

Eating behaviours and attitudes are learnt during childhood. Research has identified that those parents of children with CF report eating and mealtime behaviours as more problematic than parents of healthy children (Stark et al. 1997). It has been speculated that a preoccupation with food and weight gain in childhood may result in adverse attitudes towards food and eating as the child grows up (Crist et al. 1994). Learned food avoidance in children may be a vulnerability factor in the development of eating difficulties in later life (Bernstein & Borson, 1986).

Malnutrition in CF is complex and seems to have both organic and psychosocial contributing factors. Both factors will have a significant impact on the disease process if they are not managed effectively, as illustrated in the downward spiral on the model towards the terminal phases of the disease. The model further exemplifies the potentially harmful impact of any eating psychopathology, either symptoms of anorexia nervosa or bulimia nervosa, that may lead to weight loss or the maintenance of low weight in patients with CF. For individuals with both CF and eating disorder symptomatology the medical problems could seriously impede the individuals' health status and could potentially be fatal. The consequences associated with the potential comorbidity of the two disorders seem to dictate the need for investigation and understanding of any potential DEABs in individuals with CF.

#### 1.2 Diagnostic Eating Disorders

Eating disorders (EDs) are complex and multi-faceted clinical presentations that continue to remain ill-understood. Eating disorders included in the Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition (DSM-IV; American Psychiatric Association [APA], 1994) are: anorexia nervosa, bulimia nervosa and eating disorders not otherwise specified (EDNOS). EDs typically affect females and have an approximated prevalence of about 0.3-1% for anorexia nervosa and 1-3% for bulimia nervosa (Cotrufo, Barretta, Monteleone & Maj, 1999; Hoek, 2006).

All the EDs share a distinctive core psychopathology which is similar for adolescents, adults, males and females in that the individuals judge their self-worth in terms of their shape, their weight and their ability to control these features (Fairburn, 1997). The aetiology of EDs is multi-determined and no single cause has been identified.

#### 1.2.1. Anorexia Nervosa.

Anorexia Nervosa (AN) is a complex disorder characterised by weight loss and food restriction. Individuals present as having an intense fear of gaining weight and describe a disturbance in the experience of their own body (APA, 1994). Please refer to Table 1 for further details of the disorder.

#### 1.2.2. Bulimia Nervosa

Bulimia Nervosa (BN) is an ED characterised by out-of-control behaviour regarding food. Similarly to AN, the individuals experience a fear of fatness. The individuals experience episodes of over-eating that may be counteracted by methods of weight reduction which include self-induced vomiting and laxative abuse. For some individuals it is accompanied by non-purging behaviours such as fasting and excessive exercise. Please refer to Table 2 for further details of the disorder.

Tables 1 and 2 present the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, APA 1994) and ICD-10 (International Classification of Diseases, WHO, 1992) diagnostic criteria for AN and BN.

**Table 1.** Anorexia Nervosa Criteria

#### **DSM-IV-TR**

#### **ICD-10**

- 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).
- a. Body weight is maintained at least 15% below that expected (either lost or never achieved), or Quetelet's bodymass index is 17.5 or less. Prepubertal patients may show failure to make the expected weight gain during the period of growth.
- b. Intense fear of gaining weight or becoming fat, even though underweight.
- b. The weight loss is self-induced by avoidance of 'fattening foods'. One or more of the following may also be present: self-induced vomiting; self-induced purging; excessive exercise; use of appetite suppressants and/or diuretics.
- 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.
- c. There is body-image distortion in the form of a specific psychopathology whereby a dread of fatness persists as an intrusive, overvalued idea and the patient imposes a low weight threshold on himself or herself.
- d. In postmenarcheal females, amenorrhoea, i.e. the absence of at least three consecutive menstrual cycles. (A woman is considered to have amenorrhoea if her periods occur only following hormone, e.g. oestrogen, administration.)
- d. A widespread endocrine disorder involving the hypothalamic pituitary gonadal axis is manifest in women as amenorrhoea and in men as a loss of sexual interest and potency. (An apparent exception is the persistence of vaginal bleeds in anorexic women who are receiving replacement hormonal therapy, most commonly taken as a contraceptive pill.) There may also be elevated levels of growth hormone, raised levels of cortisol, changes in the peripheral metabolism of the thyroid hormone, and abnormalities of insulin

#### secretion.

e. If onset is prepubertal, the sequence of pubertal events is delayed or even arrested (growth ceases; in girls the breasts do not develop and there is a primary amenorrhoea; in boys the genitals remain juvenile). With recovery, puberty is often completed normally, but the menarche is late.

Table 2. Bulimia Nervosa Criteria

#### **DSM-IV-TR**

#### **ICD-10**

- a. Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following: (1) 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; (2) 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).
- a. There is a persistent preoccupation with eating, and an irresistible craving for food; the patient succumbs to episodes of overeating in which large amounts of food are consumed in short periods of time.

- b. Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as selfinduced vomiting; misuse of laxatives, diuretics, enemas, or other medications; fasting or excessive exercise.
- b. The patient attempts to counteract the 'fattening' effects of food by one or more of the following: self-induced vomiting; purgative abuse, alternating periods of starvation; use of drugs such as appetite suppressants, thyroid preparations or diuretics. When bulimia occurs in diabetic patients they may choose to neglect their insulin treatment.
- c. The binge eating and inappropriate compensatory behaviours both occur, on average, at least twice a week for 3
- c. The psychopathology consists of a morbid dread of fatness and the patient sets herself or himself a sharply

months.

defined weight threshold, well below the premorbid weight that constitutes the optimum or healthy weight in the opinion of the physician. There is often, but not always, a history of an earlier episode of anorexia nervosa, the interval between the two disorders ranging from a few months to several years. This earlier episode may have been fully expressed, or may have assumed a minor cryptic form with a moderate loss of weight and/or a transient phase of amenorrhoea.

d. Self-evaluation is unduly influencedby body shape and weight.e. The disturbance does not occurexclusively during episodes of AnorexiaNervosa.

#### 1.2.3. Eating Disorder Not Otherwise Specified (EDNOS)

Eating disorder not otherwise specified (EDNOS) is a broad category used to describe individuals who do not fully meet the criteria for either AN or BN, yet still have an eating disorder. Those with EDNOS have negative body image issues and may meet some of the criteria for AN, but have regular menses or remain normal weight despite significant weight loss, or may meet criteria for BN but binge or purge less than twice a week for three months, and/or may binge but not use compensatory behaviours (Woolsey, 2002).

1.3 Disturbed Eating Attitudes and Behaviours (DEABs)

Disturbed eating is defined as the behaviours, attitudes and perceptions that an individual demonstrates which delineate AN and BN but do not meet the criteria for a clinical diagnosis. Disturbed eating attitudes and behaviours (DEABs) refer to disturbances in attitudes related to shape, weight, body image, or food and related behaviours. These include compensatory strategies such as purging, excessive exercise, food restriction and bingeing, but not at level or combination required for a clinical diagnosis of an ED. DEABs are also referred to in the literature as 'subclinical eating disorders', 'atypical eating disorders', 'partial syndromes', and 'disturbed eating attitudes and behaviours (DEABs)'. This review will use the term 'DEABs'.

The prevalence of DEABs in the general population is much higher than AN or BN and has been found to be prevalent in the adolescent population with rates between 40-47% (Serdula et al. 1993; Thompson & Smolak, 2001). Studies have indicated a continuum between eating disturbance and later developed eating disorders (Catterin & Thompson, 1994).

Some healthcare professionals may refer to a client as having an ED even if they do not meet diagnostic criteria. In clients with CF it is important that even if they do not meet the diagnostic criteria they are assessed, as they may still be at nutritional risk and may require professional interventions aimed at addressing their DEABs.

Behaviours and attitudes such as dietary monitoring, food preoccupation and programmed exercise regimes are prescribed components of care for individuals with CF. These behaviours become dysfunctional when they are used inappropriately for weight loss, are

carried to excess, interfere with activities of daily living or become a health risk (APA, 2000).

#### 1.4 Theories of Eating Disorders

The causes of EDs are complex; it would seem that environmental, socio-cultural, psychological and genetic factors play a role in predisposing clients to ED symptoms. Conceptualisations seem incomplete at this stage and vary depending on whether they consider the development or maintenance of the eating difficulties.

#### 1.4.1. Bio-psychosocial Model.

In the beginning of the twentieth century AN was mainly conceptualised within biological and medical domains (Vandereycken, 2002). EDs have been shown to run in families and genetic epidemiological studies suggest that to some extent EDs are heritable (Wade, Bulik, Neale & Kendler, 2000). Twin and family studies indicate that predisposing factors contribute moderately to the aetiology of EDs (Eley, Collier & McGuffin, 2002).

Personality types have also been linked to EDs and Wonderlich (2002) suggests that individuals with AN are often obsessional, socially inhibited, compliant and emotionally restrained whereas individuals with BN are often more impulsive, interpersonally sensitive and low in self-esteem. However, although many different personality traits are

associated with EDs, it is difficult to distinguish traits that predispose to the illness from those which are a consequence of the disorder (Sohlberg & Strober, 1994).

Many researchers have argued that the cultural pressure on women to be thin is an important condition for the development of EDs (Crisp, 1983; Garfinkel & Garner, 1982). Epidemiological studies have shown that EDs appear to be more prevalent in Western countries, where thinness and dieting is promoted (Szmukler & Patton, 1995). However, the cultural hypothesis is being challenged as identified by Keel and Klump's (2003) meta-analysis which concluded that there is little evidence that AN is a culture-bound syndrome. The bio-psychosocial perspective is incomplete and does not lead to a carefully integrated account of the various processes leading to the development of EDs.

#### 1.4.2. Starvation and Dieting Theories.

Based on prospective studies, dieting has been linked to the development of EDs (Fairburn, 1997). However, this conceptualisation is controversial. The Continuity Theory suggests that the risk of developing an ED is proportional to the severity of dieting and is based on observations that culturally acceptable dieting may merge with what is considered pathological thinness (Nasser & Katzman, 2003). However, the Discontinuity Theory considers that dieting leads to the development of EDs only in the presence of other risk factors (Stice, Burton, Lowe & Butryn, 2007).

Starvation theories suggest that EDs are maintained by biological and physiological changes that arise from the neuroendocrine abnormalities which accompany starvation (Frichter, Pirke, Pollinger, Wolfran & Brunner, 1990).

These theories highlight the inter-relationships between psychological and physiological aspects of EDs and provide support for physical treatment, including the re-nourishment of individuals with EDs. However, re-nourishment will not address the precipitating or sustaining psychosocial aspects of EDs.

#### 1.4.3. Life-Cycle and Transition Theories.

Life-cycle theories suggest that a build-up of stress at particular points in the life cycle may precipitate the onset of an ED (Crisp, 1983; Dare, 1985). Adolescents in particular may have difficulties dealing with the physical and emotional changes that coincide with the transition to adulthood. Authors of life-cycle theories suggest that an ED allows adolescents to avoid the challenges of adolescence.

Dare (1985) suggests that the development of an ED provides families as a whole with a period of respite, where routines and roles appropriate to a previous stage of the family life cycle may continue to be used. This allows families to maintain the 'status quo' rather than approach the challenging negotiations and changes appropriate to the next stage of the cycle. The main critique of this model seems to be that it does not explain the emergence of EDs before or after the onset of puberty.

#### 1.4.4. Psychoanalytic/Psychodynamic Theories.

A psychoanalytic perspective offered by Bruch (1973) suggests that the psychodynamics which underpin AN stem from early childhood experiences. Bruch (1973) suggests that early developmental problems resulted in a disruption of an individual's emotional and physiological experience of food and satiation. Inappropriate reciprocal feedback between mother and child around feeding may result in disturbances in hunger awareness, affecting the development of autonomy or inner-directedness. Bruch (1973) believes that clients with AN experience their bodies as not entirely their own but under the influence of others. Behaviours associated with AN are seen as a way of undoing feelings of passivity, ineffectiveness and control by outside forces. There is however, a significant lack of evidence for this dysfunctional parent-child relationship.

#### 1.4.5. Cognitive Behavioural Models.

Stewart's (2005) cognitive behavioural model of child and adolescent EDs represents a combination of the models from the adult literature (Wilson & Fairburn, 2002) and draws from important concepts in developmental psychology (Lask & Bryant-Waugh, 2000). The model assumes that adolescents are vulnerable to EDs by predisposing individual factors, including low self-esteem, perfectionism, past obesity and environmental factors, including physical abuse, sexual abuse, neglect, parental under-involvement or over-protection, parental criticism and high expectations, parental conflict and family pressures to be thin. It is thought that a combination of individual and environmental factors leads

to the development of negative beliefs and assumptions that start to develop during childhood and are activated by critical stressful events.

Once core beliefs and assumptions have been triggered these have been argued to contribute to regular negative automatic thoughts. Cognitive distortions including all-ornothing, over-generalisation, personalisation, magnification and emotional reasoning appear to contribute to the development of behavioural factors of dietary restraint. These behaviours and thought patterns are then maintained by various emotional, behavioural, family and social factors. The main critique of the general CBT model is that many individuals hold similar beliefs and have similar experiences but do not necessarily go on to develop EDs.

The most validated adult model of CBT for EDs is Fairburn's (1997) model for BN. This has been further developed to form a 'transdiagnostic' model (Fairburn, Cooper & Shafran, 2003) attempting to cover all the variants of EDs. This may be particularly useful in conceptualising EDs and DEABs as it does not restrict diagnosis to either AN or BN. Fairburn et al. (2003) suggests that the underlying core psychopathology remains the same for all the types of EDs and this psychopathology is expressed in similar attitudes and behaviours.

1.4.6. Family Theories.

The family systems theory of AN suggests that organisational features of the family may be predisposing or maintaining factors for the ED. Minuchin, Rosman and Baker (1978) worked with families with adolescents with AN. They believed that families of children with EDs were often enmeshed, rigid and over-protective and it was these factors that contributed to the development of an ED.

Palazzoli (1974) also explored the features of families with an adolescent with AN, suggesting that families were often static and that the self-starvation of an adolescent arose when the system was seriously threatened by change and the challenges associated with it. Both Minuchin and Palazzoli emphasise the overly close nature of family relationships, the blurring of intergenerational boundaries and tendencies to avoid overt conflict in contributing to the development of EDs.

Although these perspectives offer interesting conceptualisations of the family structure and process, there is very little evidence to support the 'dysfunctional family' as causing AN or BN (Eisler, Le Grange & Aisen, 2003; Lock, Le Grange, Agras & Dare, 2001).

Further research has shown that there are various patterns of family organisation associated with EDs. Steiger, Leung and Houle (1992) suggest that families with adolescents with AN tend to be more controlled and organised whilst families with adolescents with BN tend to be more chaotic, conflicted and critical. Eisler et al. (2003)

suggest these patterns may actually represent the families' attempts to cope with the ED once it has developed and often seem to maintain the dysfunctional eating patterns.

Therefore, it seems the apparent psychopathology in these families is as a result rather than a cause of the problem (Bryant- Waugh, 2000). There is no evidence of the dysfunctional family as causative in the development of EDs; however, this assumption is sometimes made inappropriately when the therapy which addresses these areas of functioning is effective.

# 1.4.7. Summary

A conceptualisation of an ED should aim to reflect the complex interplay over time of the major causative and maintaining factors. Bryant-Waugh & Lask (2007) suggest that exploring predisposing, precipitating and perpetuating factors offers a useful conceptualisation of the various forms of EDs. Although the various theories seem to offer useful explanations, no single model explains all the factors and their interactions. It may be that various parts of these theories in combination with the CF model of the aetiology of malnutrition (Anthony et al. 1999) can offer an understanding of the development and maintenance of DEABS in individuals with CF. In particular combing the psycho-social and physiological aspects of CF, which will be discussed later with some of the theoretical aspects of the development of EDs may be useful in understanding the development of eating difficulties in individuals with CF.

### 1.5 Diabetes Mellitus & Other Chronic Health Conditions & DEABS

EDs have been found in individuals with other chronic health conditions that focus on dietary management as part of the treatment regime. Type 1 diabetes mellitus is an autoimmune disorder in which the pancreas stops producing insulin, which causes the body to be unable to use glucose normally (Mahan & Escott-Stump, 2004). Most individuals with Type 1 diabetes require insulin injections for the rest of their lives as well as specialised exercise, diet, and weight maintenance plans to keep blood glucose levels normal.

The requirement of following a strict diet and frequent monitoring of blood sugar levels may cause some individuals with type 1 diabetes to become overly aware of their diets and intake (Rodin et al. 2002). As in CF, this over-emphasis of one's dietary intake and disease treatment has been hypothesised to potentially lead to eating disturbances (Schlundt, Rowe, Picher & Plant, 1999).

EDs in individuals with diabetes has been explored; some studies report that EDs are more prevalent and persistent among those with type 1 diabetes compared to the general population (Jones, Lawson, Daneman, Olmsted & Rodin, 2000; Rosmark et al. 1986; Lloyd, Steel & Young, 1987). However, other studies report that the risk is no greater than in the general population (Preveler, Fairburn, Boller & Dunger, 1992; Meltzer et al. 2001). A recent review indicated that females with type 1 diabetes are not at risk of developing AN or BN, but did report that EDNOS is prevalent in this population (Nash & Skinner, 2005). It seems that DEABs are more common among females with type 1

diabetes than males (Lorini, d'Annunzio, Cartona, Castellani, & Severi, 1993). Bingeing and purging are reported to be the most common types of eating disturbances among females with type 1 diabetes (Jones et al. 2000; Wing, Norwalk, Marcus, Koeske & Finegold, 1986; Preveler et al. 1992; Steel, Young, Lloyd & MacIntyre, 1989). Individuals with diabetes and DEABs have also been reported to restrict insulin as a weight control method (Fairburn, Preveler, Davis, Mann & Mayou, 1991; Preveler et al. 1992; Steel et al. 1987; Steel, Young, Lloyd & MacIntyre, 1989).

Young- Hyman and Davis (2010) reviewed the risk factors for EDs in diabetes and suggest that the treatment exposes individuals to situations and emotions known to be associated with the development of DEABs. These risk factors include feelings of a loss of control (Vamado et al. 1997), loss of autonomy with over-involvement of parents, family, and spouses (Surgenor, Horn & Hudson, 2002), increased perfectionism regarding self-care behaviours (Crow, Keel & Kendall, 1998) and lower self-esteem and poorer body image (Erkolahti, Ilonen, & Saarijärvi, 2003). These risk factors may relate to the experiences of individuals with CF and may therefore place them at higher risk of developing eating difficulties.

In summary, eating disturbances are prevalent amongst individuals with diabetes, although these may not meet formal diagnostic criteria of EDs. Treatment management in diabetes focuses on exercise, diet and weight and so therefore this is not that dissimilar to that of CF. However, the main way in which CF differs from diabetes is the progressive

and eventual fatal nature of the disease which may explain why the prevalence rates for CF and eating disorders is lower.

Celiac disease affects 1 out of every 120-300 people in Europe and America (Escott-Stump, 2002). Individuals with celiac disease are not able to tolerate or digest gluten. Foods containing gluten include wheat, rye and barley. The result of the disease is often a long-term restrictive diet that is gluten free. The dietary restriction, along with gastrointestinal problems may make individuals more vulnerable to developing DEABs. Research exploring this population is very limited, which in itself may suggest that there is not a need to study this group of patients. However, a single case study (Ricca et al. 2000) and a cross-sectional study (Karwautz et al. 2008) have indicated moderate levels of DEABs in this group. This therefore indicates tentative evidence that those illnesses with a focus on dietary management, may contribute to a vulnerability to the development of DEABs.

Inflammatory bowel diseases (IBD) and Irritable Bowel Syndrome (IBS) are further disorders that have a focus on dietary intake. IBD including Crohn's disease and ulcerative colitis are two major chronic intestinal disorders of unknown aetiology. IBD involves a prescribed dietary regimen and usually a pharmacological agent. Dietary management of both IBS and IBD include regular eating patterns and avoiding offending foods. Although there is a heavy focus on diet and weight management in the treatment of these disorders there is little evidence to suggest that diagnostic eating disorders are more prevalent in the IBD or IBS population (Sullivan, Blewett, Jenkins & Allison, 1997;

Perkins, Keville, Schmidt & Chalder, 2005). However, this may due to a lack of studies exploring these populations. It is important to highlight that there are however some studies that have found body image dissatisfaction and eating disturbances in individuals with IBD and IBS (Boyle & Bouvard, 2003; Gilbert & Miles, 2002).

Chronic illnesses such as CF and diabetes have been proposed as being precursors to eating disorder symptomatology and DEABS due to the heavy emphasis placed on dietary intake (Herpertz et al. 1998; Striegel-Moore, Nicholson & Tamborland, 1992). Diabetes management focuses on exercise, diet and weight control, all features that are similar to the treatment in CF.

Furthermore, there is a link between diabetes and DEABs that influences the research with individuals with CF and eating disorders because of the co-morbidity of CF and CF-related diabetes. It has been reported that 85-95% of individuals with CF develop CF-related diabetes (Sinaasappel et al. 2002; Creveling et al. 1997).

Treatment and management of many diet related chronic health conditions require a commitment to a dietary regimen, usually for most of the individuals' life. The pressures associated with these regimens may be a factor in causing individuals to develop unhelpful thoughts towards food, body image and eating behaviours. Standard CF care emphasises the importance of weight and food intake and therefore some clinicians and researchers suggest that these individuals may be more vulnerable to the development of DEABs (Bryon, Sheaer & Davies, 2008).

# 1.6 Physiological Risk Factors to Developing DEABs in CF

Eating attitudes and behaviours related to the disease process or treatment regimen that are likely to be associated to weight loss or maintenance of low weight have been reported. Thomas and Bishop (2007) report that a low appetite during infections is common in individuals with CF. Furthermore, Durie and Pencharz (1989) stated that even in periods when individuals with CF are free from infections they often do not have large appetites. They also identified that some individuals are prone to complications that limit appetite.

Some individuals with CF describe feeling full easily (Pumariega, Pursell, Spock & Jones, 1986) which may be related to the delayed gastric emptying associated with gastro-intestinal symptoms (Anthony et al. 1999). Individuals with CF often experience gastrointestinal problems which cause significant abdominal pain and disturbed bowel habits, which may also contribute to reduced or low appetite, avoidance of certain foods and overall reduced food intake (Murphy & Wooton, 1998).

Abbott et al. (2000; 2007) suggest that the increased energy requirements in individuals with CF contribute to individuals experiencing excessive pressure from others to eat. The group with CF reported receiving significantly more pressure to eat than the control group and females reported a greater pressure than males. However, it was reported that the increased pressure from others to eat was actually associated with lower BMIs which suggests that this is an ineffective strategy in addressing dietary intake in individuals with

CF. It seems that all these factors lead to quite aversive experiences with food and eating which may contribute to DEABs in the long term.

# 1.7 Psychosocial Risk Factors to Developing DEABs in CF

It has been suggested that children and young people with chronic health conditions have almost three times the risk of developing emotional and behavioural difficulties when compared to their healthy peers (Cadman, Boyle, Szatman & Offord, 1987) and individuals with CF are no exception (Berge & Patterson, 2004). However, despite the burden of illness and the treatment requirements, there has been consistent evidence to show that adolescents with CF are generally a psychologically well-adapted and well-functioning group, reporting a high quality of life (Blair, Cull & Freeman, 1994). Aspects of CF may however make individuals more vulnerable to developing eating disorder symptomatology due to increased exposure to risk factors (Shearer & Bryon, 2004).

Mood disorders and poor emotional well-being have been associated with individuals with eating disorders (Polivy & Herman, 2002). Researchers have identified the presence of anxiety and depression in individuals with CF (Pumariega et al. 1986; McCollum & Gibson, 1970; Olmsted et al. 1976; Pearson, Pumariega & Seilheimer, 1991). Pearson et al. (1991) found that when compared with healthy control groups, patients with CF aged 16 to 40 demonstrated more frequent symptoms of anxiety and depression. However, Anderson, Flume and Hardy (2001) report that the prevalence of depression in individuals with CF is no higher than that found in the general population.

It is thought that those with CF may have higher levels of anxiety and mood disturbances due to the stressful situations and life events that they have experienced, including loss and bereavement (Goldbloom, 1988). Individuals with EDs report more premorbid life stresses and difficulties than do controls (Raffi, Rondini, Grandi & Fava, 2000; Schmidt, Tiller, Blanchard, Andrews & Treasure, 1997; Welch, Doll & Fairburn, 1997). The intensive regime for individuals with CF may also place significant restrictions on life and daily activities which may further contribute to feelings of low mood. It has been suggested that emotional disturbance in individuals with CF may become more severe as individuals pass from their late teens to their early twenties (Strauss & Wellische, 1980; Cowen, Lotyczewski & Weissberg, 1984).

Research has shown an association between eating disorders and perfectionism (Fairburn, 1997). It is thought that individuals with CF may be vulnerable to developing perfectionistic tendencies towards their treatment regimens as the disease usually involves strict, time consuming daily dietary and respiratory treatments (Burke et al. 1989).

Low self-esteem could also be a risk factor for DEABs (Grilo, 2006). Medical conditions could contribute to individuals feeling more vulnerable and may impact on their body image and sense of self. Disturbances in the sense of self are regarded by some researchers as central to EDs (Geist, 1989; Goodsitt, 1985). Diabetes research has shown that some individuals experience disturbances in their body and self-image (Tebbi, Bromberg, Sills, Cukierman & Piedmonete, 1990). The physical illness often contributes to a failure to thrive in childhood and a lack of appropriate weight gain may contribute to

delayed puberty, which in turn may also contribute to low self-esteem in individuals with CF (Dodge, 1992).

Conditions such as diabetes mellitus and CF require close attention to dietary intake and insulin management and so a greater preoccupation with food may be a result of the disease management and treatment. It has been suggested the children and adults with CF require 120-150% over the recommended daily allowance for caloric intake; these daily requirements produce a necessary preoccupation with diet, which has been shown to be a risk factor in the development of DEABs (Schlundt et al. 1999). Individuals may also become aware that reducing or manipulating their medication may result in weight loss. Bryon et al. (2008) and Gilchrist and Lenney (2008) state that treatments in CF can be manipulated for weight control purposes, such as the failure to take enzymes, dietary supplements or insulin. The ability to lose weight as a result of medication non-adherence may perpetuate an ED, mask its presence and contribute to adverse medical conditions (Rodin, Craven & Littlefield, 1991).

### 2.0 Method

This review utilises a systematic search strategy to explore the literature surrounding CF and EDs and DEABs. The approach summarises different primary studies from which conclusions are drawn, and has a qualitative rather than quantitative style.

# 2.1 Literature Search Strategy

The electronic databases PsychINFO, PUBMED, Medline, EBSCOhost, and Web of Knowledge were searched to provide coverage of the most current literature up to January 2012. Cochrane and PsychLit databases were also searched with the use of the internet search engine Google for non-scientific literature. The search strategy used the key terms, 'cystic fibrosis', 'eating disorder(s)'. 'eating behaviour' 'eating attitudes', 'mealtime behaviours', 'males and females', 'gender differences', 'children & adolescents', 'adults', 'nutrition', and 'malnutrition'. The electronic search was also followed by a manual search of publications citied in the papers that met the search criteria.

# 2.2 Inclusion and Exclusion Criteria

Qualitative, quantitative, or mixed methods papers were included if: (a) they involved children, adolescents or adults with CF; (b) described or measured participants or parents views, expressions or feelings relating to eating; (c) were contained in peer-reviewed

journals and (d) were published from 1978 because this is when clinicians started to take an interest in eating attitudes and behaviours among individuals with CF.

Papers were excluded if: (a) the paper combined data from people with a range of long term chronic health conditions unless findings for those with CF were reported separately; (b) book chapters; (c) conference abstracts, which provide limited information to examine the study's methodologies and results; and (d) non-English language documents.

### 3.0 Results

The articles accepted for inclusion for the review were considered in terms of a) diagnostic eating disorders in individuals with CF and b) disturbed eating attitudes and behaviours in individuals with CF across the age span (children, adolescents and adults).

# 3.1 Diagnostic Eating Disorders

Eight articles were found which explored diagnostic eating disorders in CF. These included five cross-sectional questionnaire or structured interview studies, two case studies and one review paper of a service. In the cross-sectional studies samples ranged in size from 20 (Steiner, Rahimzadeh & Lewiston, 1990) to 97 (Pearson et al. 1991). All included a mix of males and females, apart from the two case studies which both focused on females.

Standard CF care emphasises the importance of weight and food intake, therefore, some clinicians and researchers have suggested that individuals may be more vulnerable to the development of EDs (Shearer & Bryon, 2004); however, some studies have found no evidence of diagnostic EDs in the CF population.

Raymond et al. (2000) utilised a robust methodology of structured interviews in their study which found that no participant met diagnostic criteria for either AN or BN in a sample of 58 participants with CF when compared to a control group. Results from the Eating Disorder Inventory (EDI; Garner, Olmsted & Polivy, 1983), found that healthy

control participants were actually more concerned with being thin than the CF participants. The study concluded that there was no evidence for elevated rates of EDs in individuals with CF.

Shearer and Bryon (2004) and Bryon et al. (2008) used the Child Eating Disorder Examination (CEDE; Cooper, Cooper & Fairburn, 1989) to identify whether EDs were present in a sample of 55 adolescents with CF. The CEDE is a structured interview and is considered the gold standard in assessing clinical EDs in the general population. The study reported that no participant met the diagnostic criteria for AN or BN. However, one male participant did meet the criteria for EDNOS. It may have been that the sample of 55 was too small to identify accurate prevalent rates of EDs in CF populations.

Steiner et al. (1990) also assessed 10 individuals with CF for EDs and compared CF participants with individuals with AN. This study was based on the theory that the two illnesses have similar features including malnutrition and delayed pubertal development. No participants with CF met the DSM-III (APA, 1987) criteria for AN or BN. However, one parent scored their daughter in the pathological range on the Slade Anorexic Scale (Slade, 1973). Steiner et al. (1990) concluded that individuals with CF are distinctly different from AN clients and do not present with ED psychopathology. Furthermore, White, Miller, Smith and McMahan (2009) assessed psychopathology in 53 children and adolescents with CF using the computer aided diagnostic interview schedule for children (C-DISC; Shaffer, Fisher, Piacentini, Schwab-Stone & Wicks, 1990) and concluded that

no participant met the criteria for either AN or BN. It is important to note that these studies did not assess for EDNOS or other eating disturbances.

Pearson et al. (1991) used the Eating Attitude Test (EAT; Garner, Olmsted, Bohr, & Garfinkel, 1982), a test used to distinguish anorexic from non-anorexic individuals, to assess eating difficulties in a sample of 97 children, adolescents and adults with CF.

Participants were divided into two groups; the first group included children and adolescents aged between 8 and 15 and the second group included adolescents and adults aged between 16 and 40. Pearson et al. (1991) reported elevated scores indicating significant levels of ED symptomatology consistent with AN in 16.4% of the younger participants and 2.8% of the older participants. This study indicated that eating difficulties may be more prevalent in adolescent CF populations compared to adult populations. The older group did however demonstrate a greater prevalence of symptoms of anxiety and depression. These results may need to be interpreted cautiously as the EAT is a self-report measure rather than a diagnostic interview and the sample was mostly male.

Two case studies describe two females with CF presenting with diagnostic EDs. In the Gilchrist and Lenney (2008) case study, the 15 year old female had been diagnosed with AN which was having significant impact on her general health and lung functioning. It is presumed that she met formal diagnostic criteria; however, they do not state what tool was used to establish the diagnosis. The authors identify several psychosocial factors that may have contributed to the development of the ED, including systemic issues. An older study, Golbloom (1988) focuses on a 24 year old female diagnosed with a bulimic

subtype of AN in which they had used both the EDI (Garner et al. 1983) and the EAT (Garner et al. 1982) to establish behaviours including vomiting, abuse of laxatives, diuretics, diet pills and vigorous exercise. They suggested that depression may have been a significant contributing factor in the development of these disordered behaviours.

Although case studies can be useful, it may be that the idiosyncratic factors relevant to these cases are not applicable to the general CF population.

Pumariega et al. (1986) provides further evidence for EDs in the CF population. These authors state that over three years 13 adolescents attending the service met the criteria for atypical EDs in accordance with the DSM-III criteria (APA, 1987). ED symptoms included marked weight loss, food avoidance, amenorrhea and denial of emaciation. The authors noticed many of the individuals were also experiencing co-morbid depressive symptoms. Therefore, it may be that symptoms relating to appetite might actually be related to depression rather than an ED; however, this was not explored within the study. In summary the studies have used a range of ED measures and structured interviews to explore EDs with individuals with CF. However, it seems that most of the studies had very small samples which may have contributed to difficulties in generating accurate prevalent rates. At present it seems that EDs have been reported in individuals with CF; however, these have generally been at rates equal to or lower than the general population.

# 3.2 Disturbed Eating Attitudes & Behaviours (DEABs)

There has been more evidence of DEABs in both child and adult CF populations; although this may also be at lower or similar levels to the general population.

## 3.2.1 Children & Adolescents.

Thirteen articles were reviewed to explore DEABS in children and adolescents with CF.

These included five cross-sectional questionnaire or interview studies, seven
observational studies and one review paper of a service. The cross-sectional studies
samples ranged in size from 36 (Steinhausen & Schindler, 1981) to 117 (Ward et al.
2009) and in the observational studies samples ranged in size from 25 (Sanders, Turner,
Wall, Waugh & Tully, 1997) to 108 (Duff, Wolfe, Dickson, Conway & Brownlee, 2003).
All included a mix of males and females and varying age groups.

In Drotar's (1978) study exploring adaptational issues in children and adolescents it was identified that out of a sample of 32 individuals with CF, only one young person presented with symptoms of AN and nausea which were initially seen as symptoms of the disease process. Steinhausen & Schindler (1981) also found evidence of DEABs in children and adolescents with CF in their study exploring psychosocial adaptation of young people with CF. After identifying that more than one third of their sample displayed severe emotional disorders compared to only 11% of the control group, they reported that 16.7% (6 participants) of the CF group presented with disorders of eating.

In a re-analysis of the data from the study by Shearer & Bryon (2004) Bryon et al. (2008) found that 53% of the participants aged between 11 and 17 reported some disturbed eating attitudes and 16% displayed disturbed eating behaviours. Of those participants with a BMI less than 17.5, 5% were avoiding weight gain. Furthermore, 11% of all the participants felt fat, despite not being overweight, 16% were attempting to lose weight or maintain their weight, 5% were engaging in compensatory behaviours such as exercising or misusing pancreatic enzyme medication to facilitate weight loss and one female reported binge-eating over a two month period whilst attempting to restrict her intake.

Bryon et al. (2008) state that this observed rate of attitudinal disturbance was slightly higher than the general population although the study did not use a control group to establish an accurate comparison. They concluded that although diagnostic EDs were not prevalent in the CF population, significant DEABs were present.

Truby and Paxton's (2001) study included children aged between seven and 12 years old and the authors administered the Children's Eating Attitude Test (ChEAT; Maloney, McGuire & Daniels, 1988) and the Children's Body Image Scale (CBIS; Truby & Paxton, 2001). Although, no child with CF scored within the range of a diagnostic ED psychopathology in comparison to 6 participants from the control group, some concerning DEABs were reported. Of the children whose BMIs were below the 10<sup>th</sup> percentile, 75% of the females and 62% of the males did not think they were too thin and perceived their bodies to be larger than their actual size. Although these are concerning results, it seems

that the children with CF had very similar body attitudes and eating behaviours to the participants in the healthy control group.

Although it seems DEABs may be present in the CF child and adolescent population, Raymond et al. (2000) found no eating difficulties in a sample of 58 adolescents with CF. Raymond et al. (2000) reported that the healthy control sample actually presented with significantly higher scores on measures of body image and eating behaviour.

It has been suggested that the emphasis placed on increasing the calorie intake in children can result in behavioural problems at mealtimes in younger children with CF (Bowen & Stark, 1991). Studies have indicated that parents of children with CF will tend to view their child's behaviour as more problematic at meal times and generally more stressful than parents who do not have a child with a chronic illness (Crist et al. 1994).

Duff et al. (2003) observed three age groups of children with CF and found that parents of children with CF reported more problematic meal time behaviours compared to parents of healthy control children. It was also noted that parents of boys reported more problems than those of girls. Problems included a lack of enjoyment of eating, poor appetite, preferring to drink than eat, snacking and negotiating. The authors also reported that in response to these difficulties the parents would often engage in ineffectual and counterproductive strategies including coaxing and therefore unintentionally rewarding unwanted behaviour that is likely to maintain the eating difficulties and may contribute to further difficulties later in the child's development.

Powers et al. (2002) studied 35 infants and toddlers with CF and again parents of the children with CF reported more problematic meal time behaviours compared to the healthy control group. In this comparison study it was identified that the children with CF took longer to eat meals, were unwilling to try new foods, had a smaller appetite and preferred liquids to food. Parents were left feeling extremely frustrated and this contributed to a lack of confidence in managing their child's dietary intake.

Stark et al. (1995) also explored caloric intake, behavioural eating styles and parental perception of eating behaviour in school-age children compared to healthy control participants. The participants with CF were found to have longer meal times and a slower pace of eating. Parents of the children with CF reported eating behaviours and patterns, such as dawdling and refusing food as much more intense than the parents of the control children. Stark et al. (1995) concluded that the children with CF, although eating above the dietary recommendations, spent more time at the dinner table, took more time to complete their meals and exhibited high intensity ratings of mealtime behaviour.

Sanders et al. (1997) observed 25 children aged between one and seven years with CF and their parents and compared them with a healthy control group and a group of children with feeding problems without CF. Again parents of children with CF reported more problematic meal time behaviours. However, objective observations identified no differences between the children with CF and the two control groups. It was however observed that mothers of the CF children engaged in higher rates of aversive interactions than the non-clinic control group. Sanders et al. (1997) concluded that parents of children

with CF may feel increased pressure to promote eating, which results in a higher rate of instruction giving and that this over time may increase the non-compliance in children. Ward et al.'s (2009) larger study of 117 children with CF and their parents also provides further support for a higher frequency of and more intense problematic mealtime behaviours in their sample of children aged 6 months to five years old.

It may be that parental views of their child's eating behaviours are distorted by the emphasis and perceived pressure by health professionals regarding the importance of their child's dietary intake and the need for weight gain (Chase, Long & Lavin, 1979).

This is supported by the findings from studies using more objective observations and relying less on parental reports which suggest that children with CF do not present with any more behavioural feeding problems than their healthy peers. Powers et al. (2005) in particular identified that there were no significant differences in the total number of problematic mealtime behaviours between children with CF and a healthy control group. The authors however reported that there was a difference in parental behaviours during meal times, with the parents of the children with CF providing a higher frequency and rate of commands to eat. Stark et al. (2000, 2005) also stated that there were no significant differences in the mealtime behaviours of children with CF and a healthy control group. However, children with CF took longer to eat their meals, were unable to meet the recommended dietary intake and the parents used more direct and indirect commands of eating. Stark et al. (2000) suggest that children with CF and their parents

engage in an escalation of 'typical' parent-child behaviours, therefore typical parenting strategies may not be sufficient to meet the dietary requirements of children with CF.

## 3.2.2. Adults.

Five articles were reviewed to explore DEABS in adults with CF. These included three cross-sectional questionnaire studies and two qualitative studies. Of the cross-sectional studies samples ranged in size from 221 (Abbott et al. 2000) to 1049 (Walters, 2001). The focus group study (Berge, Patterson, Goetz & Milla, 2007) included 17 participants and the individual interview qualitative study (Willis, Miller & Wyn, 2001) included 40 participants. All included a mix of males and females of varying age groups.

Abbott et al. (2000) used an adapted version of the Eating Attitude Test- 26 (EAT; Garner et al. 1982) to access eating difficulties in a large CF population of 221 adults and healthy controls. After factor analysis, six items were removed from the original EAT measure to make it more appropriate for the CF population. A score of above 11 was used on each subscale of this adapted EAT-26 as indicative of significant eating difficulties. Abbott et al. (2000) reported that in the CF sample, 4% of males and 13% of females were considerably restricting their dietary intake and 6% of males and 11% of females reported binge eating and intended vomiting with an intense preoccupation with food. In comparison to the control group however, these rates were significantly lower. Furthermore, the female CF sample reported being satisfied with their body shape and the males with CF desired to be heavier, whereas the control females desired to be slimmer

and control males were content with their size. They did however identify that females with CF were generally happy with their perceived shape and weight and identified that these individuals were often low in weight.

Abbott et al. (2007) compared four groups of individuals; CF individuals receiving enteral tube feeding, CF individuals taking oral supplements, CF individuals receiving no nutritional interventions and age-matched healthy controls. Using the adapted EAT (from Abbott et al. 2000), it was reported that the CF participants receiving nutritional interventions desired to be heavier and engaged in less dieting. Excessive dieting was only reported in 11% of the enteral tube feeders and 6% of the dietary supplement group in comparison to 17% in the CF control group and 36% of the healthy controls.

Therefore, Abbott et al. (2007) concluded that individuals with CF and poor nutritional status may be less likely to report DEABs than nutritionally 'healthier' individuals with CF. In the author's two studies (Abbott et al. 2000; 2007) only a minority of individuals with CF reported eating difficulties and they therefore concluded that individuals with CF generally appeared to be well adapted. The main critique of these two studies was the use of the EAT; despite it being an adapted version, the EAT has not been validated on a CF population.

Willis et al.'s (2001) qualitative interview-based study explored the impact of CF on young people aged 16 to 21. Significant gender differences were identified as a main theme in the study. The authors reported that females were more likely to follow a low-calorie diet and think that their weight was adequate despite looking very thin.

Specifically, they reported that 66% of the females followed a low-calorie diet in comparison to only 21% of males. They identified that males were actually keen to increase their body size and strength.

Berge et al. (2007) used focus groups to explore gender differences in young adults' perceptions of living with CF during the transition into adulthood. On exploration of body image seven of the eleven female participants identified that body image was a significant concern for them. Four of the female participants reported that weight was also a concern for them and spoke of losing weight. One female participant reported 'I was anorexic for a while.... I barely ate anything' (p. 198).

Walters (2001) large postal survey study of adults with CF also identified significant gender differences in that a high proportion of females with CF who were very underweight (<85% ideal body weight) or underweight (85-94% ideal body weight) perceived themselves as being normal or overweight. This is in stark comparison to a high proportion of males who were normal weight and perceived themselves to be underweight. These results indicate the possible presence of a distorted body image amongst individuals with CF; it seems that men tended to underestimate their weight whilst women tended to overestimate. This may mean that females are at greater risk of malnutrition and may not be as motivated to adhere to dietary treatment plans. Walters (2001) concluded that the perception of the self as underweight is an important factor in determining nutritional behaviour and this perception differs between the sexes.

All five studies indicate to some extent the evidence of DEABs within the adult CF population, although this may still be lower in comparison to healthy control samples. The presence of DEABs in comparison to the very low rates of diagnostic EDs found in CF populations however suggest that DEABs are a clinical issue that need to be addressed and explored. Any behaviour that may negatively impact on health in an individual with CF is of significant concern to the individual and the health care team supporting the individual.

# 4.0 Discussion

CF is a multidimensional, lifelong illness, not only affecting the physiological aspects of the individuals' body but emotional and psychological aspects as well. The complex inter-play between DEABs and the physical implications in individuals with CF is still not clear. The review has reported conflicting results in terms of DEABs and diagnostic EDs in the CF population. Some studies report that individuals with CF are at an increased risk for atypical EDs such as EDNOS (Abbott et al. 2007; Shearer & Bryon, 2004). However, other studies report that the prevalence of EDs in CF do not differ significantly from rates in the general population (Bryon et al. 2008; Abbott et al. 2000; Raymond et al. 2000). One evident finding is some DEABs do exist in some individuals with CF. The types of DEABs found in the review include atypical eating disorder behaviours, food avoidance, preoccupation with food, bulimic tendencies, body image distortions and misuse of pancreatic enzyme therapy. These types of behaviours can be very damaging for the health of individuals with CF.

## 4.1 Methodological Considerations

Although a relatively large body of literature was reviewed in order to explore the relationship between CF and eating behaviours and attitudes, a number of methodological considerations were identified which may have confounded the findings and which make it difficult to draw a firm conclusion.

Many of the studies only used very small sample sizes or failed to include control groups, or more specifically failed to use weight-matched control subjects, limiting the understanding of the findings. It is also difficult to generalise findings when only small samples have been assessed. Furthermore, there seems to be an age bias in the current published findings with very few studies exploring adult populations. This may be due to the life-limiting nature of the disease in the past. However, as discussed previously the life expectancy of individuals with CF has been significantly increased over the past two decades and adult populations are therefore increasing and becoming more relevant for study.

Although many of the studies used well established, standardised measures and interviews the wide variety makes it difficult to draw direct comparisons due to the conceptual and diagnostic differences of the various tools. Additionally, current published ED measures are not appropriate for CF populations. Using measures developed for the general population means there is the potential for misclassifications of behaviours and attitudes. For example measures reflecting eating disturbances may in fact reflect skills and attitudes learned as part of the self-care regimen within CF management. The currently available published measures do not assess problems specific to the disease process and treatment of CF and further fail to explore issues related to avoiding high-fat foods due to associated gastrointestinal symptoms, experiencing low appetite due to infections or experiencing pressure to eat from others. It is these attitudes and behaviours that are CF specific and are not related to eating disorder psychopathology. It is difficult to see the validity of using an instrument developed for use with an ED population with a

disease-specific population without validating its appropriateness for a CF population.

Unfortunately, it appears that studies that have examined the link between EDs and CF have utilised standardised ED measures without first validating their applicability to the CF population.

It may be that those studies that utilised an interview process instead of self-report measures were able to probe further into the eating behaviours and attitudes to assess whether or not they were due to ED symptomology or disease-specific behaviours and attitudes. The studies that utilised self-report measures will not have gathered detailed information and will have left gaps in current understanding of the eating difficulties that may be experienced by individuals with CF. Furthermore, self-report measures may have limited validity in a psychiatric condition that incorporates secrecy as part of its presentation. However, self-report measures are generally provided at a lower cost and can be easily administered within a busy clinical environment. There is currently a lack of measures or interviews appropriate for populations with chronic health conditions and comorbid eating difficulties.

The studies in the review were identified due to their high quality and importance in demonstrating the relationship between CF and eating behaviours, but the limitations identified must be taken into account when making conclusions about the link between CF and DEABs. It would seem that these issues could be addressed in future research.

### 4.2 Clinical Implications

Although it would seem that EDs that meet either DSM-IV or ICD-10 criteria are not prevalent in individuals with CF there is some indication that some individuals do present with significant DEABs. Due to the potential negative impact on the person's health it is important that clinicians and health teams provide support to these individuals. Support is essential to prevent their symptoms from worsening and to help individuals with CF develop healthy attitudes towards eating and their bodies.

It may be that a screening policy should be introduced within services for DEABs to promote early detection of any difficulties. Considering the continuum of DEABs to EDs, some authors have recommended screening for DEABs as part of the routine of the annual CF nutrition assessment (Bryon et al. 2008). An assessment of an individual's behaviour and attitudes towards eating, weight and shape may be an initial step in identifying those who may be at risk of developing DEABs.

Individuals' attitudes towards eating, shape and personal appearance need to be taken into consideration rather than simply focusing on calorie intake and weight gain. It may be that those identified as struggling with their eating would receive joint interventions from both clinical psychologists and dieticians.

If DEABs are identified, members of the CF team can provide support in modifying behaviours and beliefs regarding eating, weight, shape and body image. If AN or BN is identified and diagnosed the individual will most likely require a referral to professionals skilled in the treatment of EDs. Collaborative working will be required between the nutritionists, medics and clinical psychologists to support the individual in an effective

and beneficial manner. It would seem that the treatments available to the general population (e.g. Cognitive Behaviour Therapy, Family Therapy and Cognitive Analytic Therapy) with EDs would be mostly transferable to individuals with CF; however, these may need to be adapted in order to incorporate the more specific aspects of the disease. It would also be essential that the clinician has an understanding of the disease process.

High-calorie diets are not encouraged by current Western social culture and therefore this would need to be explored within treatment with the individual. Recent national initiatives against obesity, influence school teaching and therefore healthcare teams should inform children with CF about why they are different to their peers in terms of digestion, calorie consumption and energy usage. It is difficult for the individual with CF to balance both social messages from the media regarding image and diet with the demands placed upon them by the health professionals in terms of managing their illness.

### 4.3 Future Directions

Further research is warranted in this area and in particular research needs to explore whether there is a trade-off between body image and treatment adherence. Especially as current research indicates females are happy with their slim figures (Abbott et al. 2000, 2007; Willis et al. 2001). Therefore, it would be beneficial to explore whether females with CF do not adhere to dietary recommendations or exploit their treatment regimens to remain slim. This may offer further explanation for the differing survival rates of the different genders. CF-created low weight may be perceived as ideal, especially in a

society focusing on slimness. However, this may lead to individuals compromising their health status for slimness, by not adhering to dietary advice or utilising other aspects of treatment to maintain their low weight.

There is currently a lack of longitudinal studies as most of the published papers are correlational studies. It would be of significant clinical interest to explore whether children presenting with problematic meal time behaviours later develop eating difficulties as they transition through the various life cycles into adulthood.

Evaluation, characterisation and classification of DEABs in individuals with CF holds clinical importance. Current research has not identified any factors that may be related to DEABs in individuals with CF and conclusions at this stage can only be drawn from research examining the general population. Focusing on identified gaps in future research of DEABs in this population could improve clinical care for this serious comorbid condition. It is therefore clinically important to identify those at risk of developing DEABs.

Further qualitative studies could aim to offer insight into the unique experiences of individuals experiencing DEABS. It could be hypothesised that CF individuals may be more protected from developing diagnostic EDs due to the high frequency of contact with health professionals . This research might explore the close interactions an individual has with their healthcare team to understand the protective factor that this offers.

# 5.0 Conclusion

The literature reviewed has provided a comprehensive account of the links between CF and diagnostic EDs and DEABS. The evidence suggests that DEABs are present in CF populations. However, the available research does not indicate increased diagnostic EDs in the CF population. Previous studies reporting on the nature and prevalence of EDs are likely to represent an underreporting of incidence or a failure to accurately describe eating difficulties in the CF population due to the methodological limitations identified (Bryon et al. 2008).

For individuals with both CF and ED symptomatology the medical problems could seriously impede the individuals' health status and could potentially be fatal. The consequences associated with the potential comorbidity of the two disorders seem to dictate the need for further investigation and understanding of any potential DEABs in individuals with CF.

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# Eating Attitudes and Behaviours in Males and Females with Cystic Fibrosis.

The Role of Body Image and Coping Styles.

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#### **Abstract**

Developing an understanding of the relationships between eating behaviours, body image and coping styles in individuals with Cystic Fibrosis (CF) could offer valuable guidance for prevention and intervention programmes aimed at reducing disturbed eating attitudes and behaviours (DEABs) in this population. This study investigated the relationships between these variables and further explored gender differences. A sample (N=109) of mainly Caucasian males and females with CF completed six self-report measures. Statistical analysis involved, group comparison, correlation and multiple regression techniques, the latter of which explored the moderated effect of gender. Females presented with higher rates of DEABs than males; however males reported poorer body image. Key findings indicated a significant association between DEABS and body image and coping styles. Specifically, individuals with high levels of DEABs reported higher levels of body dissatisfaction and engaged in a higher degree of unhelpful coping styles. As such the potential benefit of psychotherapeutic interventions aimed at addressing eating behaviours and attitudes, body image attitudes and coping styles are discussed. Areas of future research are also identified and discussed. The importance of early intervention for individuals at risk of developing DEABs is highlighted due to the associated health risk in combination with CF.

## 1.0 Introduction

#### 1.1 Overview

There have been few studies exploring disturbed eating attitudes and behaviours (DEABs) within individuals with CF. Clinical eating disorders (EDs) have been found within the CF population but generally at rates equal to or lower than the general population (Bryon, Shearer & Davies, 2008). Even though rates are lower the potential health risks associated with any disturbed eating attitudes and behaviours emphasise the importance of understanding this comorbid presentation. DEABs have been found in individuals with CF (Abbott et al. 2000, 2007; Byron et al. 2008). However, there have been no studies exploring other variables that may be related to those individuals who present with higher rates of DEABs.

## 1.2 Cystic Fibrosis and Nutrition

Cystic Fibrosis (CF) is a life-threatening genetic disorder that is associated with respiratory and digestive problems and consequently inadequate nutrition and poor growth. Poor nutritional status has been linked with decreased survival (Durie & Pencharz, 1992; Elborn & Bell, 1996). Between 85% and 90% of clients with CF have pancreatic maldigestion and malabsorption of nutrients, particularly of dietary fats and fat-soluble vitamins (Borowitz, 1994). Achieving and maintaining an ideal nutritional status and body weight is an integral part of the treatment of CF. The treatment therefore

may contribute to a preoccupation with food and weight, both of which are fundamental characteristics of individuals with eating disorders (Shearer & Bryon, 2004).

The management of nutrition hinges on the maintenance of body weight and therefore a high energy, high fat diet is prescribed. Oral pancreatic enzymes are taken with food to aid the absorption of nutrients. Malnutrition is managed with fat-soluble vitamins and oral feed supplements and/or where required, nocturnal enteral feeding (Abbott et al. 2007). Some individuals with CF also develop CF-related diabetes which can be a further cause of nutritional failure due to the associated physical symptoms (Anthony, Paxon, Catto-Smith & Phelan, 1999).

Malnutrition resulting from malabsorption and maldigestion tends to result in low Body Mass Index (BMI). Having a healthy nutritional status can help improve overall health and lung function (Murphy, Wooton, Bond & Jackson, 1991). However, with social messages supporting a preference for slenderness, non-adherence to pancreatic enzyme supplements, nutritional supplements, and/or dietary recommendations may occur in order to achieve, or maintain, CF-induced slenderness.

#### 1.3 Theoretical Overview

Many factors are interrelated in the malnutrition of individuals with CF. Anthony et al. (1999) have developed a model to illustrate the complex interactions between physiological and psychosocial aspects that may make an individual vulnerable to developing DEABs. In relation to the psychosocial aspects of this model it is conceptually useful to refer to the CBT transdiagnostic model (Fairburn, Cooper &

Shafran, 2003) of EDs to offer further detailed understanding of the psychological factors that may be important in the development and maintenance of DEABs, including body image and coping styles.

## 1.4 Disturbed Eating Attitudes and Behaviours (DEABs) and Cystic Fibrosis

Disturbed eating is defined as the behaviours, attitudes and perceptions that an individual demonstrates which delineate Anorexia Nervosa (AN) or Bulimia Nervosa (BN), but do not meet the criteria for a clinical diagnosis. Disturbed eating attitudes and behaviours (DEABs) refers to disturbances in attitudes related to shape, weight, body image, or food and related compensatory behaviours, although not to the level or combination required for a clinical diagnosis of an eating disorder.

In Drotar's (1978) study one young person was identified out of a sample of 32 patients as presenting with symptoms of AN. Steinhausen & Schindler (1981) also found evidence of DEABs in children and adolescents with CF in their study exploring psychosocial adaptation of young people with CF. In their sample 16.7% of young people with CF presented with disorders of eating.

A re-analysis of the data from the study by Shearer and Bryon (2004) Bryon et al. (2008) found that 53% of the participants aged between 11 and 17 reported some disturbed eating attitudes and 16% displayed disturbed eating behaviours. Byron et al. (2008) reported that DEABs occur in individuals with CF at a slightly higher rate than the

general population stating 53% in the CF sample, compared to 40-47% in the general population (Childress, Brewerton, Hodges & Jarrell, 1993; Serdula et al. 1993).

Although it seems DEABs may be present in the CF child and adolescent population Raymond et al. (2000) found no eating difficulties in a sample of 58 adolescents with CF. Abbott et al. (2000) used an adapted version of the Eating Attitude Test- 26 (EAT; Garner, Olmsted, Bohr & Garfinkel, 1982) to access eating difficulties in a large CF population of 221 CF adults and 148 healthy controls. Abbott et al. (2000) reported that in the CF sample, 4% of males and 13% of females were considerably restricting their dietary intake and 6% of males and 11% of females reported binge eating and intended vomiting and an intense preoccupation with food. However, in comparison to the control group, these rates were significantly lower. In the author's two studies (Abbott et al. 2000; 2007) only a minority of individuals with CF reported eating difficulties.

In a qualitative interview-based study Willis, Miller and Wyn (2001) reported that females were more likely to follow a low-calorie diet. Specifically, they reported that 66% of the females followed a low-calorie diet in comparison to only 21% of males.

The studies indicate to some extent the evidence of DEABs within the adult CF population with a higher rate in females; although this may still be lower in comparison to healthy control samples. The presence of DEABs in comparison to the very low rates of diagnostic EDs found in CF populations however suggest that it is a clinical issue that needs to be explored and addressed.

## 1.5 Coping Styles and Cystic Fibrosis

Coping styles refers to behaviours, thoughts and feelings that individuals utilise to avoid being harmed by life stressors. Different ways of coping serve to prevent, avoid or control emotional distress (Abbott, Dodd, Gee & Webb, 2001). Various coping styles have been described in the literature, but there appears to be a general agreement that styles form a continuum with an avoidance-passive-helpless way of coping at one end of the spectrum and an active-monitoring-optimistic approach at the other (Lazarus, 1966; Scheier & Carver, 1985; Miller & Mangan, 1983). Generally, active-optimistic styles are viewed as more positive and avoidance-denial as more negative and maladaptive in the general population.

Coping with the demands of CF can be quite challenging, individuals with CF are expected to manage the complex treatment regimen that accompanies the physical demands of the disease as well as coping with the more emotional and social aspects of the illness. Major disease-specific stressors for these individuals can include hospital admissions, physiotherapy, monitoring and implementing high-fat diets, medical treatments and longer term complications of the disease.

Researchers have suggested that the use of particular coping strategies in populations without chronic illnesses' may contribute to the onset and progression of eating psychopathology (Troop, Holbrey, & Treasure, 1998). In particular, it has been found that styles focused on avoidance are associated with dieting, binge eating and higher scores on questionnaires such as the Eating Attitude Test (Garcia-Grau, Fuste, Miro, Saldona &

Bados, 2002). Many etiological models of disordered eating include poor coping skills as an important component in its development (Hawkins & Clement, 1984; Stice, 1994).

Studies of adherence may offer insight into the impact of coping styles on disease management in individuals with CF. Early studies using physician ratings of coping in individuals with CF found no or very weak relationships between coping styles and treatment adherence (Moise, Drotar, Doershuk & Stern, 1987; Pinkerton, Duncan, Trauer, Hodson & Batten, 1985). However, studies using self-reported measures of coping and adherence have found stronger relationships. Coping styles such as denial have been found to be associated with persistent treatment non-adherence (Friedman & Litt, 1986) and optimistic styles have been correlated with greater overall treatment adherence (Pownceby, 1996; Czajkowski & Koocher, 1986).

Abbott et al. (2001) discovered that the degree of adherence to treatments in individuals with CF was influenced by a person's style of coping. Individuals with avoidant and distraction coping styles were less likely to adhere to treatment which included nutritional management. Therefore, how an individual copes with CF has the potential to influence the management of the disease, including dietary management. Abbott et al. (2001) reported that similar coping styles were reported by males and females, except for the use of distraction strategies that were employed to a greater extent by females.

## 1.6 Body Image and Cystic Fibrosis

Body image has been described as a multifaceted concept that includes thoughts, feelings and behaviours related to the appearance and functioning of one's body (Cash, 1994; Cash & Pruzinsky, 1990). Body image disturbance is usually defined as an inaccurate internalised representation of one's weight, shape and appearance which tends to lead to body dissatisfaction (Thompson, Heinberg, Altabe, Tantleff- Dunn, 1999). Things such as an accident, injury, disease (e.g. CF), early puberty, or a high BMI may be a trigger to the development of dissatisfaction with an individual's body image (Thompson et al. 1999; Cash & Pruzinsky, 2002).

Research in the general population has shown a strong correlation between body image and eating disorders (Ricciardelli & McCabe, 2001; Slade & Brodie, 1994). In support of this Stice and Hoffman (2004) state that studies have demonstrated that body image dissatisfaction is the most consistent predictor of the onset of DEABs.

Previous research has shown body image is extremely important to adults and adolescents (Abbott et al. 2000; Snarey, MacDonald, Harris & Weller, 1993; Sawyer, Rosier, Phelan & Bowes, 1995, Wenninger, Weiss, Wahn & Staab, 2003) and children with CF (Truby & Paxton, 2001). Willis et al.'s (2001) and Abbott et al.'s (2000) studies of individuals with CF found that females were generally happy with their slender body shape and did not wish to gain any weight and a number of the females wanted to lose weight irrespective of their current weight. However, males were generally less happy with their perceived weight and shape and wanted to gain weight and become more muscular and

strong. Abbott et al. (2000) also concluded that individuals with lower body dissatisfaction scores showed increased issues with food and eating behaviours.

Walters (2001) large postal survey study of adults with CF also identified significant gender differences in body image. A high proportion of females with CF who were very underweight (<85% ideal body weight) or underweight (85-94% ideal body weight) perceived themselves as being normal or overweight while a high proportion of males who were normal weight perceived themselves to be underweight. These results indicate the possible presence of a distorted body image amongst individuals with CF. Walters (2001) suggests that this may mean that females are at greater risk of malnutrition and may not be as motivated to adhere to dietary treatment plans.

Truby and Paxton (2001) used the Children's Body Image Scale (Truby & Paxton, 2001) and found that compared to healthy controls, children with CF were more satisfied with their body image and there were no gender differences.

Berge, Patterson, Goetz and Milla (2007) used focus groups to explore gender differences in young adults' perceptions of living with CF during the transition into adulthood. On exploration of body image seven of the eleven female participants identified that body image was a significant concern for them.

Research in individuals with CF seems to reflect the differing social-cultural messages for males and females. For males there is an emphasis on the body's functional capacity, whilst females are judged in terms of aesthetics (Abbott & Barber, 2010). This seems to

result in females wishing to be slim and males desiring to be larger and more muscular (Gray & Ginsberg, 2007).

In Tierney's (2011) review of the literature on body image in people with CF she concluded that males reported poorer BMI compared to females and healthy male controls. She suggested that male body dissatisfaction may place them at risk of steroid abuse to obtain a more muscular physique but she highlights studies exploring this issue are currently lacking. Tierney (2011) also concluded that CF females generally had better body image satisfaction than healthy peers and males with CF and refers to their low weight as an explanation of this satisfaction. However, valuing a slender frame has many associated risks in CF (Beker, Russek-Cohen & Fink, 2001) and may therefore contribute to the poorer survival reported amongst females with CF compared to males (Demko, Byard & Davis, 1995).

Simon et al. (2011) explored whether young people with CF are more likely to adhere to dietary recommendations depending on their gender and body satisfaction and concluded that body satisfaction may play a role in nutritional intake and eating behaviours and attitudes. In particular they identified that females may be content with their slimmer figures despite recommendations for weight gain, while males desire to be larger and more muscular, which is more congruent with medical and dietary advice.

1.7 Quality of Life (QoL) and Cystic Fibrosis

Life expectancy has dramatically improved in individuals with CF over the last couple of decades and the focus has shifted from simply keeping individuals alive to enhancing their quality of life. Quality of life (QoL) is a multi-dimensional measure integrating self-reported physical, emotional and social functioning and well-being (WHOQoL, 1995). QoL is of interest to clinicians and researchers as individuals may maintain a good QoL in spite of being seriously ill (Wahl, Rustoen, Homme & Hanestad, 2003).

Findings from the general population with eating disorders have generally reported a negative association between symptoms of an eating disorder and QoL (Mond, Hay, Rodgers, Owen & Beumont, 2004; 2005). In particular, eating disorders are associated with significant psychosocial impairments affecting social relationships, emotional well-being and general mental health (Hay, 1998).

Pfeffer, Pfeffer and Hodson (2003) suggest that the impact of CF on QoL will depend on many factors including their subjective health perception, coping style and social and psychological support. Coping has emerged as an important factor in explaining some of the QoL domains in individuals with CF. A high level of optimism was associated with a better health-related QoL and high levels of distraction with a poorer health-related QoL (Abbott, Hart, Morton, Gee & Conway, 2008). Females with CF have reported a poorer quality of life than males on several health related QoL domains of generic and disease specific scales (Modi & Quittner, 2003; Gee, Abbott, Conway, Etherington & Webb, 2003).

It may be that disturbed eating attitudes and behaviours in combination with chronic illness further impacts on QoL. No previous research has examined the associations between eating behaviours and attitudes and QoL in individuals with CF.

## 1.8 Formulation of Current Study

The presence of DEABs in individuals with CF could potentially be linked to poorer treatment compliance, greater physical health risks and poorer QoL. In view of this it is important to understand the factors that might contribute to the development of DEABS in this population. Two variables have been highlighted in the literature as potentially impacting the development of DEABS; coping styles and body image. However the potential relationship between DEABs, coping styles and body image in individuals with CF has yet to be explored. The potential impact of gender differences has also not been explored. This study therefore aims to explore the relationships between DEABs, coping styles, body image and QoL in individuals with CF by testing the following hypotheses.

## 1.9 Hypotheses

H1: Females with CF are more likely to have higher rates of DEABs compared to males with CF.

H2: Males with CF are more likely to report poorer body image compared to females with CF.

H3: Eating behaviours and attitudes in males and females will be related to coping styles. Avoidance or distraction coping styles will be associated with DEABs. Optimistic-acceptance and hopefulness coping styles will be associated with non-disturbed eating attitudes and behaviours. There may be gender differences in these relationships.

H4: Individuals with DEABs will have poorer body image than individuals with non-disturbed eating attitudes and behaviours. There may be gender differences in this relationship.

H5: Individuals with DEABs will have poorer physical and psychosocial quality of life than individuals with non-disturbed eating attitudes and behaviours.

## 2.0 Method

## 2.1 Design

In order to test the hypotheses the study used a cross-sectional, correlational questionnaire design. The predictor variables were gender and eating behaviour. The outcome variables were coping style, body image and quality of life. Independent variables of age, Body Mass Index (BMI), forced expired volume<sup>1</sup> (FEV<sub>1</sub>), pancreatic insufficiency and whether the participant has CF-related diabetes were also measured to enable further exploratory analysis of the data.

## 2.2 Setting

Participants were recruited from the Southampton Regional Cystic Fibrosis Clinics and the CF hospital ward. The adult service had an approximate caseload of 180 individuals and the child service had approximately 15 young people aged 14 and over.

## 2.3 Sample

#### 2.3.1. Inclusion and Exclusion Criteria.

Inclusion criteria for this study were that participants were aged 14 and over and were being seen in a specialist CF clinic with an established diagnosis made by a medical professional. Exclusion criteria were participants who were not able to speak or read English and individuals who displayed evidence of a significant learning disability (i.e. in

 $<sup>^1</sup>$  Forced expired volume is the amount of air which can be forcibly exhaled from the lungs in the first second of forced exhalation. It is used as an indicator of lung functioning. In healthy adults expected FEV<sub>1</sub> would be 75-80%.

contact with learning disability services) as identified by a member of their clinical care team.

## 2.4 Sample Size

Green (as cited in Tabachnick & Fidell, 2007) suggest a minimum of 108 participants for a multiple regression with four predictors, assuming a medium effect size for the relationship between the independent variables and the dependent variables, a p < .05 and power of 0.8. Given the time available for this study and the potential difficulties in recruiting people with CF to engage in research (Anthony et al. 1999), a sample size of 108 was targeted to ensure enough power for calculations.

#### 2.5 Recruitment

All eligible participants with an appointment at a clinic or receiving care as an inpatient were invited to participate in the study. The clinic appointments were routine CF clinics and annual reviews. Individuals with CF attended these clinics at least once every three months in accordance with CF Trust (2001) guidelines.

Eligible participants were identified by a member of the clinical care team with reference to the study inclusion and exclusion criteria and the individual's suitability for the study (individuals who the clinical care team felt it was inappropriate to invite for other reasons such as poor health or recent adverse life events were not invited to participate.). All eligible and suitable participants were sent an invitation letter (appendix A and B) and participant information sheets (appendix C, D and E) at least two weeks before their

scheduled appointment. Participants were not offered any financial or other incentive to take part in the study and were invited to contact the researchers for any further information.

## 2.6 Participant Characteristics

Demographic information including age, gender, ethnicity and work status was provided by the participants. More specific clinical information including, weight, height, FEV<sub>1</sub>, any use of enteral feeding, whether the individual experienced pancreatic insufficiency and whether the individual had CF diabetes were collected from the participants' medical notes.

Of the 131 individuals with CF approached for participation in the study, 121 agreed to participate. Of these 121 participants 10 failed to return the completed questionnaires. The study recruited 111 participants; however, two participants were excluded from the final analysis after their medical notes had been examined and it was discovered they had not received a complete medical diagnosis of CF. Of the 109 participants included in the final analyses, the final group consisted of 50 (45.9%) males and 59 (54.1%) females with a mean age of 28.5 years (Range 15- 65 years).

Consistent with the genetic predisposition of CF, 105 (96.3%) participants were Caucasian and 4 (3.7%) were Caucasian other. Twenty-four (22%) participants were married, 54 (49.5%) were single, 27 (24.8%) participants were in a relationship, 2 (1.8%) were divorced, one (0.9%) participant was separated and one (0.9%) person was

remarried. Participants were asked to state what the highest level of education they had achieved. Eight (7.3%) had some secondary school or less, 33 (30.3%) had achieved GCSEs/O-levels, 27 (24.8%) had achieved A 'levels, 13 (11.9%) had attended higher education, 16 (14.7%) had a University degree and 12 (11%) had a received a professional qualification or completed post-graduate study.

Participants were also asked to state their work or school attendance status. Fifteen (13.8%) were attending school outside the home, one person (0.9%) was taking an educational course at home, six (5.5%) were seeking work, 55 (50.5%) were working full or part time, six (5.5%) were full time homemakers, 18 (16.5%) were not attending school or work due to health reasons and eight (7.3%) were not working for other reasons.

#### 2.7 Measures

All participants completed the following self-report measures in addition to a demographics form (Appendix F) which elicited information about age, gender, ethnicity, marital status, level of education achieved and work or school status. As highlighted in the theoretical models of the development of DEABs (Anthony et al. 1999; Fairburn et al. 2003) measures were chosen that focused on psychological concepts that may contribute to the development of DEABs. Due to the uniqueness of the population, CF specific measures were chosen where possible.

2.7.1. Eating Attitudes Test – 26 (EAT; Garner, Olmsted, Bohr, & Garfinkel, 1982).

Participants completed the Eating Attitudes Test- 26 (EAT). This is a 26 item self-report inventory of symptoms of eating disturbance. It consists of 3 subscales, *Dieting*, *Bulimia* and Food Preoccupation and Oral Control. Dieting relates to an avoidance of fattening foods and a preoccupation with being thinner. Bulimia and Food Preoccupation consists of items about thoughts of food and bulimic type behaviours. Oral Control relates to self-control of eating and perceived pressure from others to gain weight.

Participants indicated their response to each item on a 6-point Likert scale from 'Never' to 'Always'. A cut-off score of above 20 or above has been suggested to identify problematic attitudes and behaviour toward eating (Garner et al. 1982).

The EAT was originally designed to measure symptoms of anorexia but has since been found to have a 90% accuracy rate in identifying women with any DSM-IV (American Psychiatric Association [APA], 1994) eating disorder diagnosis. The measure has good test-retest reliability (Carter & Moss, 1984) and concurrent validity with other eating disorder measures (Williamson, Anderson, Jackman & Jackson, 1995). High internal consistency coefficients have been found for total EAT scores in adult female and male samples without CF (Garner & Garfinkel, 1979; Garner et al. 1982). However, studies investigating the three-factor structure in adult females have reported inconsistent findings (Garner et al. 1982; Koslowsky, Scheinberg, Bleich & Solomon, 1992; Lane,

Lane, & Matheson, 2004) and the factor structure has not been investigated in males. The alpha coefficients of each subscales are as follows of 0.79 (*Dieting*), 0.67 (*Bulimia and Food Preoccupation*) and 0.72 (*Oral Control*).

2.7.2. The Cystic Fibrosis Eating Attitudes and Behaviours Questionnaire (CFEAB; Randlesome & Bryon, 2011.)

The CFEAB (Appendix G) is a 24-item self-report measure assessing eating attitudes and behaviours relevant to the adult and adolescent CF population. Participants were asked to respond on a five-point Likert scale (ranging from never to always).

This recently developed measure has been found to display adequate psychometric properties with a three-factor structure with good internal consistencies for the subscales and the whole measure (Randlesome & Bryon, 2011). A principal components analysis was conducted to identify the three factors (see appendix H) which are *Eating Disorders* (*EDs*), *CF-related Eating Attitudes and Behaviours* (*CFEABs*) and *Appetite*. The alpha coefficients of each subscales are as follows of 0.92 (*EDs*), 0.89 (*CFEABs*), 0.77 (*Appetite*).

This is a new measure that is yet to be published and so at present there is little normative or validity data. This was used in addition to the EAT as this measure and other existing measures relating to eating difficulties are not necessarily appropriate for the CF population.

2.7.3. The Cystic Fibrosis Body Image Scale (Wenninger, Weiss & Wahn, 2003). This is a brief self-report scale assessing attitudinal body image in adolescents and adults with CF. It consists of eight items and outlines three subscales, Evaluation/Satisfaction, Importance and Trust in Physical Functioning/Health. Higher scores indicate positive body image attitudes.

It has been reported by Wenninger et al. (2003) that the test-retest correlations ranged from 0.83 to 0.88 and the internal consistencies were above 0.70, except for the domain '*importance*' ( $\alpha = 0.44$ ). This brief measure has not been used in previous research and has only been validated on people from one CF service.

2.7.4. The Figure Rating Scale (FRS; Stunkard, Sorenson & Schlusinger, 1983). The scale comprises of nine figures depicting individuals ranging in body size from very thin to very heavy (2 sets, males and females). Perceived BMI was ascertained by asking participants which silhouette is most like them and desired BMI was measured by asking participants which silhouette they would like to be. The difference was taken to be the measure of body satisfaction; bigger differences indicated higher levels of body dissatisfaction. Thompson and Altabe (1991) found that the FRS has good test-retest reliability and scores correlate with other measures of body dissatisfaction and eating disturbance.

## 2.7.5. Cystic Fibrosis Coping Scale (Abbott et al. 2001).

The Cystic Fibrosis Coping Scale is a patient-derived scale that consists of 20-items and measures four distinct ways of coping with CF in adults and adolescents. The four coping styles include *Optimistic-Acceptance*, *Hopefulness*, *Distraction* and *Avoidance* and high scores represent the coping style utilised. All subscales have shown respectable internal reliability (Abbott et al, 2001). The alpha coefficients of each subscales are as follows 0.74 (*optimistic acceptance*), 0.69 (*hopefulness*), 0.71 (*distraction*) and 0.76 (*avoidance*).

Optimistic-acceptance reflects an optimistic and determined way of coping with CF, hopefulness reflects a hope that everything will turn out for the better, distraction indicates an attempt to try and forget CF and finally avoidance suggests an avoidant and passive way of dealing with CF.

2.7.6. The Cystic Fibrosis Questionnaire – UK adults and adolescents (CFQ; Quittner, Buu, Watrous & Davis, 2000).

The CFQ is a disease specific questionnaire measuring health related Quality of Life (QoL). It has been validated for use with adolescents (aged 14 and over) and adults with CF (Quittner et al. 2000; Modi & Quittner, 2003; Quittner, Buu, Messer & Watrous, 2005). The questionnaire consists of 50 items with 12 subscales measuring aspects of health related QoL, *physical status*, *role*, *vitality*, *emotional functioning*, *eating*, *treatment*, *social functioning*, *body image*, *health*, *digestion*, *respiratory and weight*.

#### 2.8 Procedure

Individuals who had been invited to participate in the study were approached by a researcher at their clinic visit or on the hospital ward. If they agreed to participate, the individual had the opportunity to ask any further questions and then written consent was obtained. For participants under the age of 16 both an assent form and a parent/guardian consent forms were completed (appendix I, J, and K). All participants were allocated a code number which was used on all of their study data to maintain confidentiality.

Participants were given the option of either completing the questionnaires during their clinic appointment, taking them home to complete (pre-paid envelopes were provided for return) or completing the questionnaires online. The majority of the participants completed the measures in their clinic appointment or on the ward in their rooms. The participants mostly completed the questionnaires independently; however, the researchers did provide assistance if this was requested. The estimated maximum completion time for all of the questionnaires was 45 minutes; however, most participants were able to complete the measures in 20-30 minutes. The researchers either collected the completed questionnaires at the end of the participant's clinic visit or returned to the ward at a later time agreed with the participant for collection. Any questions the participants had regarding their participation and the study were answered and they were thanked for their participation.

After completion of the questionnaires the researcher accessed their medical notes to complete the clinical information sheet. The most recent information available was used when completing this form.

Due to the sensitive nature of the study, participants may have been psychologically affected or concerned after participating. In the information sheet the participants were informed that they could contact the researchers (including a clinical psychologist) should they have any concerns. Furthermore, the consent form asked whether participants agreed to be contacted by a clinical psychologist should their responses to the EAT indicate significant eating difficulties that without treatment would impact negatively on their health.

#### 2.9 Ethical Considerations

Ethical approval of the study was granted by the National Research Ethics Service

Committee South Central- Southampton A and given a favourable opinion (Ref.

11/SC/0153 & Appendix L). Ethical approval was also obtained from the Southampton

University School of Psychology University Ethics Committee. Research and

Development approval was gained from Southampton Hospital University Trust

(Appendix M).

## 2.10 Statistical Analysis Strategy

A power calculation was performed before subject recruitment. All descriptive and inferential statistics were performed using Statistical Package for the Social Sciences (SPSS) for Windows version 19.0 (SPSS, Chicago, IL). In terms of skew and kurtosis, the vast majority of the data was not within the parameters for being accepted as normally distributed. Therefore, non-parametric tests were used. Mann-Whitney analyses were used to explore gender and group differences.

To examine the association between variables, Spearman's rank correlation coefficients were computed. Although the data were not normally distributed, regression analyses were run on the data due to the stability of such analyses with non-parametric data (Allison, 1999; Howell, 1997). Only a probability level of .01 or less was accepted as significant to avoid error due to the numerous correlations.

#### 3.0 Results

#### 3.1 Clinical Variables

Health status in individuals with CF can be categorised according to participants' level of pulmonary function, which is expressed as the forced expiratory volume of air in 1 minute (FEV<sub>1</sub>) and documented as the percentage obtained compared with that predicted for age (Zapletal & Samenek, 1987). Those who obtain a percentage of 70% or more of that predicted for their age are considered to have a mild CF status, a score of 45-69% reflects a moderate CF status, whilst a score of 44% or less reflects a severe CF status. Body Mass Index (BMI) ranges (Kg/m²) can be categorised as follows (Abraham & Llewellyn-Jones, 2001): 17.5 or less, anorectic BMI range, 17.6-18.9 is considered underweight, 19.0-24.9 is the desirable BMI range, 25.0- 29.9 is overweight, 30 or more is considered obese.

The mean BMI for all participants was 21.9 (range 14.5-41.4), for females the mean BMI was 22.1 (range 17.2-41.4) and males was 21.6 (range 14.5-30.1). The mean FEV<sub>1</sub> for lung functioning was 57% (range 10-101%). Eighty-six (78.9%) participants were pancreatic insufficient and 23 (21.1%) were pancreatic sufficient. Thirty-seven (33.9%) had CF-related diabetes. Four (3.7%) participants were receiving tube feeding.

## 3.1.1. $FEV_1$ and BMI.

To confirm previous observations of people with CF, the relationship between FEV<sub>1</sub> (% of predicted) and BMI was examined. As anticipated there was a significant positive correlation between FEV<sub>1</sub> (% of predicted) and BMI percentile, r = .31, p < .01. Therefore, those with higher BMIs had better lung functioning.

# 3.1.2. Age and BMI.

In the examination of the relationship between age and BMI a significant positive correlation between age and BMI percentile was identified, r = .29, p < .01. Therefore, older participants had higher BMIs.

## 3.1.3. Diabetes and $FEV_1$ .

To explore group differences in the participants with CF-related diabetes a Mann-Whitney U test was used. The FEV<sub>1</sub> (% of predicted) in participants with CF-related diabetes (median=46.00) did differ significantly from the FEV<sub>1</sub> (% of predicted) in participants without CF-related diabetes (median=61.00), U = 950.00, z = -2.26, p < .05. The participants with CF-related diabetes therefore generally had lower lung functioning percentage compared to those without CF-related diabetes.

### 3.1.4. Pancreatic Insufficiency and BMI.

To explore group differences in the participants with pancreatic insufficiency a Mann-Whitney U test was used. The BMI in participants with pancreatic insufficiency (median=21.10) did differ significantly from the BMI in participants without pancreatic insufficiency (median= 24.10), U = 520.00, z = -3.43, p < .05. Therefore, the participants with pancreatic insufficiency generally had lower BMIs compared to the participants who were pancreatic sufficient.

## 3.2 Descriptive Statistics

Please see Table 3 for a summary of the descriptive statistics for the six measures and subscales. The visual inspection of the test scores indicated that the criteria for parametric analysis may be violated. This was confirmed by the skewness and kurtosis values of the data (see Table 3). Skewness and kurtosis values greater or less than zero indicate that a distribution differs from a normal symmetric distribution. The Kolmogorov-Smirnov test also indicated that the distributions of most of the variables were non-normal. Consequently, in subsequent analyses non-parametric tests were performed where appropriate.

**Table 3.** *Descriptive statistics of the measures and subscales.* 

Measure &	Mean	Median	Standard	Skewness	Kurtosis
Subscales			Deviation		

EAT	4.98	3.00	7.14	3.59	15.83
Dieting	2.44	1.00	4.16	4.30	23.55
Bulimia	0.5	0.00	1.57	3.98	16.31
Oral Control	2.03	1.00	3.19	2.13	4.44
CFEAB	18.04	15.00	12.00	1.70	3.21
EDs	10.22	8.00	9.29	1.20	0.78
CFEABs	.30	0.00	1.58	6.89	54.14
Appetite	3.69	3.00	3.40	1.26	1.33
<b>Body Image</b>	26.38	26.00	6.10	0.17	- 0.69
Trust	10.02	10.00	2.78	0.03	- 0.85
Importance	6.50	6.00	2.05	-0.15	-0.67
Evaluation	9.87	10.00	3.00	-0.04	-0.65
Coping Style					
Optimistic	75.84	80.95	19.25	-1.05	1.02
Hopefulness	45.97	44.44	19.84	-0.12	-0.49
Distraction	37.40	33.33	22.12	0.43	-0.15
Avoidance	35.93	33.33	32.49	32.49	-0.43
QoL					
Physical	59.29	66.66	32.45	-0.28	-1.28
Role	72.89	75.00	22.29	-0.79	0.29
Vitality	49.99	50.00	23.60	-0.17	-0.53
Emotion	72.78	73.33	21.14	-0.69	-0.23
Eating	82.71	100.00	23.10	-1.14	0.24
Treatment	59.46	55.56	22.55	-0.19	0.061
Social	69.98	72.22	19.98	-0.43	-0.90
Body	65.34	66.67	28.88	-0.42	-0.90

Health	58.00	66.66	26.38	-0.28	-0.70	
Digestion	83.99	88.89	19.51	-1.32	1.13	
Respiratory	59.13	61.11	22.14	-0.10	-0.57	
Weight	64.52	66.67	39.09	-0.51	-1.33	
FRS 1	3.73	4.00	1.36	0.51	0.27	
FRS 2	3.93	4.00	0.73	-0.35	0.03	

## 3.3 Missing Data

Some of the measures had missing data. Since there were less than 5% of data missing on each variable and its distribution appeared random, it was not necessary to subject the data set to missing values analysis (Tabachnick & Fidell, 2007).

# 3.4 Eating Behaviours and Attitudes

### 3.4.1. Correlations between the EAT and the CFEAB.

To explore the relationship between the EAT and the CFEAB scores Spearman's correlation coefficient was conducted. The EAT total and the CFEAB total were significantly positively correlated r (109) = .34, p (one-tailed) < .01. This is a medium effect size. This would be expected, as individuals who score high on one eating measure would also be expected to score high on the other.

### 3.4.2 Significant Eating Difficulties.

Four participants scored above 20 on the EAT, suggestive of significant eating difficulties and may be indicative of a diagnosable eating disorder. All four participants were female and their BMIs ranged from 17.62-25.74. This provides some support for the hypothesis predicting that females would present with more DEABs than males.

## 3.4.3. Correlations of Eating Behaviours and Attitudes and Clinical Variables

The relationships between eating behaviours and attitudes and clinical variables were explored using Spearman's correlation coefficient. Please see Table 4. Of particular note are the significant correlations between *oral control* and BMI r = -.26 p < .01 and age, r = -.33, p < 01. The CFEAB total and BMI were significantly correlated, r = .33, p (one-tailed) <.01. This suggests that those with higher BMIs experienced more DEABs. Furthermore, the subscale EDs was strongly positively correlated with BMI, r = .60, p < .01

**Table 4.** Correlations of Eating Behaviours and Attitudes and Clinical Variables.

Measure & Subscales	Clinical Variables					
	BMI	FEV <sub>1</sub>	Age			
EAT	07	09	11			
Dieting	.18	07	.13			
Bulimia	- 12	.02	19*			
Oral Control	26**	13	33**			
CFEAB	.33**	.05	01			

EDs	.60**	.23*	.12
CFEABs	04	02	09
Appetite	12	22*	17

<sup>\*</sup> *p* < .05 \*\* *p* < .01

# 3.5 Eating Behaviours and Attitudes in Males and Females

The experimental hypotheses of the study predicted that females with CF are more likely to have higher rates of DEABs compared to males with CF. To gain insight into the nature and range of the difficulties experienced with food and eating behaviours, the distribution of scores across each of the measures and the subscales for male and female are presented in Table 5.

**Table 5.** *Descriptive statistics of the EAT and the CFEAB* for males and females.

Measure &	Males			Females		
Subscales						
	Mean	Median	Standard	Mean	Median	Standard
			Deviation			Deviation
EAT	3.94	3.00	3.64	5.86	3.00	9.05
Dieting	1.80	1.50	2.08	2.98	1.00	5.29
Bulimia	0.38	0.00	1.41	0.59	0.00	1.70

Oral Control	1.76	1.00	2.56	2.25	0.00	3.66
CFEAB	13.28	11.00	7.66	22.08	19.00	13.52
EDs	7.04	4.50	7.66	12.92	10.00	9.75
CFEABs	0.00	0.00	0.00	.56	0.00	2.13
Appetite	2.78	2.50	2.74	4.46	4.00	3.72

To explore gender differences in eating behaviours and attitudes a Mann-Whitney U test was used. The EAT total in males (median=3.00) did not differ significantly from the EAT total for females (median= 3.00), U = 1450.50, z = -.15, non-significant. In terms of the subscales of each of the measures, the distribution of all the three subscales of the EAT, were also the same across the genders.

The CFEAB total however did differ significantly between males (Median=11.00) and females (Median= 19.00), U = 807.50, z = -4.07, p < .001. This showed that females experienced more DEABs than males. In terms of the three subscales there were significant differences between the genders, for the subscale EDs females scored significantly higher (median=10.00) than the males (median= 4.50), U = 891.50, z = -3.56, p < .001.

### 3.6 Body Image in Males and Females

# 3.6.1. Body Image Scale.

Please see Table 6 for a summary of the scores on the Body Image Questionnaire for males and females. To explore gender differences in body image a Mann-Whitney U test

was used. The Body image total in males (Median=27.00) did not differ significantly from the body image total for females (Median= 26.00), U=1236.0, z=-1.30, non-significant. The distribution of the body image total is the same across genders. Therefore, this does not support the original hypothesis. However, the *trust* subscale did differ significantly between males (Median=11.00) and females (Median= 9.00), U=1046.5, z=-2.48, p<.05. This showed that males had more trust in their body than females.

## 3.6.2. Figure Rating Scale.

Please see Table 6 for a summary of the scores of the FRS for males and females. To explore gender differences in the FRS a Mann-Whitney U test was used. The difference between their perceived and ideal body shapes was significantly larger for males (Median= 1.00) than females (Median= 0.00), U = 762.0, z = -3.66, p < .01. A positive score indicates a desire to be bigger; this showed that males were more likely to report wanting to increase their body size than females.

**Table 6.** Descriptive Statistics of the Body Image Questionnaire and the FRS for males and females.

Measure &	Males			Females				
Subscales	Mean	Median	SD	Mean	Median	SD		
<b>Body Image</b>	27.18	27.00	6.16	25.71	26.00	6.02		
Trust	10.80	11.00	2.80	9.37	9.00	2.60		
Evaluation	9.78	10.00	2.81	9.95	10.00	3.18		
Importance	6.61	7.00	2.34	6.39	6.00	1.78		
FRS								
Difference	0.73	1.00	1.39	-0.24	0.00	1.30		

### 3.7 Eating Behaviours and Attitudes and Coping Styles

To test the hypothesis that there would be a relationship between the eating behaviour and attitudes scores (EAT and CFEAB) and the coping style scores Spearman's correlation coefficient correlations were conducted on all four subscales of the Coping questionnaire (optimistic-acceptance, hopefulness, avoidance, distraction) for all the participants.

A negative trend was found between the EAT total and coping style responses in the *hopefulness* subscale of the CF Coping Questionnaire, r = -.20, p < .05. Therefore, indicating that those with fewer DEABs were employing the *hopefulness* coping strategy. This partially supports the hypothesis three. There was a significant correlation between the subscale *oral control* and *optimistic-acceptance* coping style, r = -0.27, p < .01. There was a positive trend between the subscale *bulimia* and *distraction* coping style, r = 0.17, p < .05.

A negative trend was found with the CFEAB and the *optimistic-acceptance* subscale, r = -.17, p < .05, suggesting that those with lower levels of DEABs utilised the *optimistic-acceptance* strategy. *Optimistic-acceptance* coping style was significantly correlated with the subscale *appetite*, r = -0.26, p < .01. *Hopefulness* and *appetite* were also significantly correlated, r = -0.25, p < .01. Therefore, indicating that those participants with fewer DEABs utilised more positive coping styles. *Avoidance* and *CFEABs* were significantly positively correlated, r = 0.24, p < .01, suggesting that those who scored higher on the CF specific eating attitudes and behaviours utilised the more unhelpful coping strategy of *avoidance*.

3.7.1. Male and Female Eating Behaviours and Attitudes and Coping Styles

Please see table 7 for a summary of the scores on the Coping Style Questionnaire for males and females. To explore gender differences in coping styles a Mann-Whitney U test was used on the four subscale. No significant gender differences were found in any of the coping styles.

**Table 7.** Descriptive statistics of the Coping Style Questionnaire for males and females.

Measure & Subscales	Males			Females		
	Mean	Median	Standard	Mean	Median	Standard
			Deviation			Deviation
Coping Style						
Optimistic-acceptance	75.90	80.95	20.62	75.79	76.19	18.19
Hopefulness	41.78	44.44	18.21	49.53	50.00	20.61
Avoidance	30.33	33.33	30.80	40.68	33.33	33.37
Distraction	35.06	33.33	23.28	39.42	40.00	21.06

When the data was examined by gender, there were no significant correlations for the males participants on the EAT. However, there were further significant findings for the females participants. A significantly negative correlation was found between the EAT total and coping style response in the *optimistic-acceptance* subscale of the CF Coping Questionnaire, r = -.37, p < .01. The associated probability level of .01 showed that such a result is highly unlikely to have arisen by sampling error, assuming the null hypothesis to be true. There was also a negative trend to a correlation between the EAT and coping style responses in the *hopefulness* subscale of the CF Coping Questionnaire, r = -.26, p < .05.

Using Spearman's correlation coefficient to explore the relationships between the total CFEAB and coping styles, two significant findings were discovered for the male participants. The level of DEABs in males was significantly negatively related to the

coping style of *hopefulness*, r = -.43, p < .01. Therefore, indicating that those utilising the *hopefulness* coping style experienced fewer eating difficulties. The level of DEABs was also significantly negatively related to the coping style of *distraction*, r = -.34, p < .01 for male participants. This suggests that those utilising higher levels of the style *distraction* also experienced fewer DEABs.

The total score for the CFEAB for females was significantly negatively related to the coping style *optimistic-acceptance*, r = -.38, p < .01. There was also a positive trend the CFEAB and the *avoidance* coping style, r = .23, p < .05, suggesting that those participants who reported utilising this strategy to higher levels also experienced more DEABs.

In terms of the subscales of the CFEAB further significant correlations were found. For males, *hopefulness* and *appetite* were negatively correlated, r = -.33, p < .01. For females, *optimistic-acceptance* and *appetite* were negatively correlated r = -.49, p < .01.

# 3.8 Eating Attitudes and Behaviours with Body Image

#### 3.8.1. Eating Attitudes and Behaviours and the Body Image Scale.

To test the hypothesis that there would be a relationship between the eating behaviour and attitudes scores (EAT and CFEAB) and body image scores Spearman's correlation coefficient correlations were conducted on the total body image score and the three subscales (*trust, evaluation, importance*) for all the participants.

There was a significant negative relationship between the EAT total score and the total body image score, r = -.28, p (one-tailed) < .01, therefore indicating that those who report more positive body image experience fewer DEABs. The subscale *evaluation* was significantly negatively related to the EAT total score, r = -.30, p (one-tailed) < .01. Furthermore, there was also a trend in the relationship between the EAT total and the subscale *trust*, r = -.18, p < .05.

The total CFEAB was significantly negatively correlated with the total body image score, r = -.41, p < (one-tailed) .01. This was further supported by two of the subscales correlating significantly with the CFEAB, trust, r = -.37, p < .01 and evaluation, r = -.34, p < .01. Furthermore, there was also a negative trend in the subscale importance, r = -.21, p < .05. There were no significant relationships between the EAT and the body image questionnaire for the male participants. There was a significant relationship between the EAT and the total body image questionnaire for the female participants, r = -.43, p < .01. This was further supported by two of subscales correlating significantly with the EAT,  $trust \ r = -.35$ , p < .01 and  $evaluation \ r = -.45$ , p (one-tailed) < .01.

The CFEAB correlated significantly with the body image questionnaire for the male participants, r = -.40, p < .01, and for the female participants, r = -.42, p (one-tailed) < .01. Furthermore, for the male participants *importance* was significantly correlated to the CFEAB, r = -.39, p < .01. There were also trends in the other two subscales, *trust* r = -.28, p < .05 and *evaluation* r = -.27, p < .05. For the female participants *trust* was

significantly correlated to the CFEAB, r = -.35, p < .01 and *evaluation* was found to be significantly related to the CFEAB, r = -.49, p < .01.

Correlations were also conducted for the three subscales of the CFEAB for both males and females. For males, trust and importance were significantly correlated to the subscale appetite, r = -.38, p < .01 and r = -.40, p < .01 respectively. For females, all three of the subscale of the Body Image questionnaire significantly correlated with the subscale appetite,  $trust\ r = -.64$ , p < .01,  $evaluation\ r = -.50$ , p < .01, and  $importance\ r = -.50$ , p < .01.

## 3.8.2. Moderated Effect of Gender.

A series of hierarchical multiple regressions were performed in order to examine the moderating effect of gender. This analysis was guided by conceptual and statistical work on interaction effects for testing moderation (Aiken & West, 1991; Baron & Kenny, 1986; Cohen, Cohen, West, & Aiken, 2003). Within the regression models the predictor variable was entered at step 1 (Body Image total score), the moderator variable at step 2 (Gender) and the interaction term at step 3 (Body Image multiplied by gender). The predictor and dependent variables were mean centred prior to computing the interaction term (Cohen et al. 2003). A significant interaction term (i.e. standardised regression coefficient  $\beta$ , as well as  $R^2$  change) indicates a moderator effect (Baron & Kenny, 1986; Frazier, Tix & Barron, 2004; Holmbeck, 1997). The results of the regression are presented in table 8.

**Table 8.** Regression to test the moderated effect of gender in Eating Behaviours and Attitudes and Body Image.

	В	SE B	β	$R^2$	R <sup>2</sup> Change
Step 1. Predictor					
Constant	00	.09			
Body Image Total	42	.09	42**	.17	.18
Step 2. Moderator					
Constant	- 1.01	.27			
Body Image Total	38	.08	38**		
Gender	.65	.17	.33**	.27	.10
Step 3. Predictor x					
Constant	- 1.04	.27			
Body Image Total	.13	.27	.13		
Gender	.66	.17	.33**		
Body Image *Gender	34	.17	54*	.28	.03

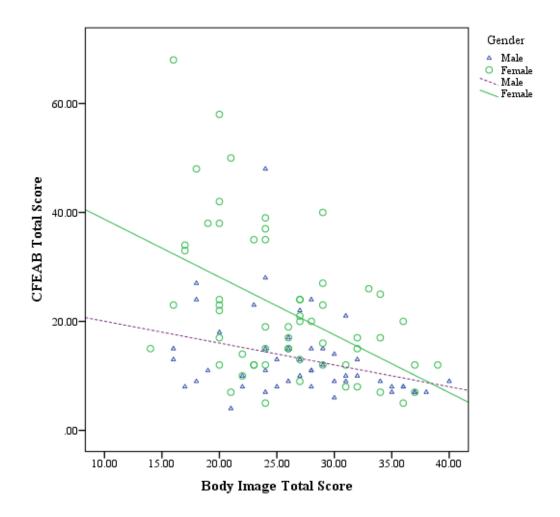
*Note. B* = unstandardised beta weights,  $\beta$  = standardised beta weights. p < .05\*, p < .001\*\*.

The model fitted the data well and did not violate assumptions of regression analysis (Berry, 1993). The interaction between body image total and gender predicted eating behaviours and attitudes, change in  $R^2 = .03$ , F change (1, 104) = 4.10, p < .05, which explained 28% of the variance in body image total scores.

The plot of the regression lines form the significant interaction between gender and body image on eating attitudes and behaviours is presented in figure 2. This demonstrates that gender has a moderating effect on eating attitudes and behaviours at varying levels of the

body image total. Participants who score higher on the body image measure score lower on the CFEAB. The significant interaction effect is more apparent in females than males.

**Figure 2**. *Interaction of gender by body image total score and CFEAB total score.* 

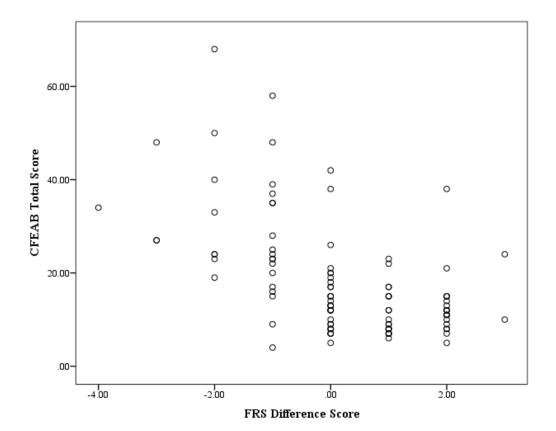


3.8.3. Correlations Eating Behaviours and Attitudes and the Figure Rating Scale

To test the hypothesis that there would be a relationship between the eating behaviours and attitudes scores (EAT and CFEAB) and the FRS scores Spearman's correlation coefficient correlations were conducted on the total body image score and FRS scores.

A significant correlation was found between the FRS and the CFEAB total, r = -.54, p < .001, see figure 3. An increasing score on the FRS means that the individual wants to be bigger in size. This suggests that participants who want to be slimmer score higher on the CFEAB. There was no correlation between the FRS and the EAT.

**Figure 3**. Scatterplot Correlation of the total CFEAB score and the FRS Difference.



# 3.9 Correlations of Eating Behaviours and Attitudes with Quality of Life

To test the hypothesis that there would be a relationship between the eating behaviour and attitudes scores (EAT and CFEAB) and Quality of life (QoL) Spearman's correlation coefficient correlations were conducted on all 12 subscales for all the participants. Please see Table 9 for the correlations of the EAT and the CFEAB and the 12 QoL subscales.

**Table 9.** One-tailed Spearman's Correlation Coefficient between the EAT & CFEAB & QoL

	Physical	Role		Vitality	Emotion	Eating	Treatment	Social	Body	Health	Digestion	Respiratory	Weight
EAT Total	26*	13	18*		11	35**	.01	09	24*	15	07	13	09
Dieting	16	.01	19*		.01	08	.04	.05	.06	08	.10	.02	.20*
Bulimia	01	14	10		12	22*	03	05	17*	03	16*	18*	15
Oral Control	26*	20*	09		14	45**	02	22*	38**	17*	13	19*	31**
CFEAB													
Total	25*	17*	22*		15	33**	05	25*	.02	19*	02	05	.21*
EDs	.08	.13	.02		.10	.17*	.13	.07	.46**	.15	.12	.24*	.58**
CFEABs	02	00	05		17	13	04	12	04	03	05	10	.00
Appetite	57**	39**	46**		32*	73**	31*	49**	38**	53**	20*	42**	24*

<sup>\*</sup> *p* < .05 \*\* *p* < .001

The analyses presented in Table 9 show there are some correlations between aspects of QoL and DEABs, suggesting that individuals who experience more DEABs also have poorer QoL. This is more apparent when the specific CF eating behaviour measure

(CFEAB) was used. In particular the subscale *appetite* on the CFEAB was significantly negatively correlated with all of the subscales of the QoL measure, indicating those scoring higher on the appetite *subscale* experienced more effects on their QoL (lower scores indicating poorer QoL). Due to the large number of comparisons it was decided that a *p* value of less than .001 would be considered as an acceptable statistical significance value. It was considered that this would address any issues related to both type 1 and 2 errors.

#### 4.0 Discussion

This study aimed to build upon previous research exploring eating attitudes and behaviours in people with CF and attempted to explore the potential influence of body image attitudes and coping styles that may be important in the development of DEABs. It sought to highlight factors underpinning the possible benefit of prevention and intervention approaches aimed at promoting and enhancing body image and coping styles as a way of reducing the likelihood of developing DEABs in individuals with CF.

### 4.1 Interpretation of Key Findings

The study found that four female participants presented with significant eating difficulties as indicated by the EAT, this is consistent with previous research which suggests that individuals with CF present with eating disorders at rates lower than the general population (Bryon et al. 2008). The results of the study however, are lower than previous findings. Pearson, Pumariega & Seilheimer (1991) found that 16.4% of young people with CF were in the symptomatic range for disordered eating on the EAT (Garner et al. 1982) and Pumariega, Pursell, Spock & Jones (1986) observed that 12% of CF patients had atypical eating patterns.

At present the recently developed CFEAB does not have a suggested clinical cut-off for significant eating difficulties. However, this measure does have strength in identifying a wider range of difficulties with eating attitudes and behaviours within the CF population.

As hypothesised, the CF specific eating measure results indicated that females experienced higher levels of DEABs than males, in particular on the subscale eating disorders. This is consistent with previous findings from Abbott et al. (2000) and Willis et al. (2001) suggesting gender differences in eating behaviours and attitudes.

The study examined gender differences in body image and no gender differences were found with the Body Image questionnaire. Previous research has indicated that males with CF generally have poorer body image than females with CF (Abbott et al. 2000 & Willis et al. 2001). However, the lack of difference found may be related to the measure used as Wenninger et al.'s (2003) original findings also failed to identify any gender differences.

The FRS however, did provide support for the hypothesis suggesting that males were dissatisfied with their current perception of their bodies and wanted to be larger. This is similar to previous research exploring body image in males with CF, in particular Abbott et al. (2000) and Willis et al. (2001) highlighted males were dissatisfied with their perceived weight and shape and wanted to gain weight and become more muscular and strong. The findings of the current study support this conclusion.

The results of the study indicated that neither of the totals of the eating measures (EAT or CFEAB) were significantly correlated with any of the measured coping styles. However, several of the subscales were related to various coping styles. On the EAT there was a significant correlation between the subscale *oral control* and *optimistic-acceptance* coping style. On the CFEAB, *optimistic-acceptance* and *hopefulness* coping styles were

significantly correlated with the subscale *appetite*. Therefore, indicating that those participants with fewer DEABs utilised more coping styles categorised as positive.

Furthermore, *avoidance* and the subscale *CFEABs* were significantly positively correlated, suggesting that those who scored higher on the CF specific eating attitudes and behaviours utilised the more unhelpful coping strategy of *avoidance*. These findings provide support for the hypothesis and are consistent with previous findings in the general population (Garcia-Grau et al. 2002) and in previous research with individuals with CF (Abbott et al. 2001).

When the data was examined by gender, a significant negative correlation was found between the EAT and CFEAB totals and coping style *optimistic-acceptance* subscale for females. The level of disturbances in eating attitudes and behaviours in males was significantly negatively related to the coping style of *hopefulness*. Therefore, indicating that those utilising the *hopefulness* and *optimistic-acceptance* coping style experienced fewer eating difficulties. The level of DEABs was also significantly negatively related to the coping style of *distraction* for male participants. This suggests that those utilising higher levels of the style *distraction* also experienced fewer eating difficulties. Previous research suggested that females were more likely to utilise distraction coping styles than males (Abbott et al. 2001).

As hypothesised there was a significant negative relationship between the EAT and CFEAB total scores and the total body image score, therefore indicating that those who report more positive body image experience fewer DEABs. This supports research

conducted on individuals without a chronic illness (Ricciardelli & McCabe, 2001; Slade & Brodie, 1994, Stice & Hoffman, 2004). When the data was explored by gender there were no significant relationships between the EAT and the body image for the male participants. However, there was a significant relationship between the EAT and the total body image questionnaire for the female participants. The CFEAB correlated significantly with the body image questionnaire for both the male and female participants. When this was examined using multiple regression it was discovered that although participants who score higher on the body image measure score lower on the CFEAB, this effect was moderated by gender and the relationship between eating attitudes and behaviours and body image was more apparent in females than males.

A significant negative correlation was found between the FRS and the CFEAB total. An increasing score on the FRS means that the individual wants to be bigger in size. This suggests that participants who want to be slimmer score higher on the CFEAB. Abbott et al. (2000) suggest that lower scores on body satisfaction and self-esteem are associated with increased issues with food and eating behaviour. The findings of this study would support this relationship.

The correlations between QoL and eating behaviours showed there were some correlations, suggesting that individuals who experience more DEABs have poorer aspects of QoL. This is more apparent when the specific CF eating behaviour measure (CFEAB) was used. This is consistent with findings from the general population with

individuals with eating disorders where it has been reported that there is a negative association between symptoms of an eating disorder and QoL (Mond et al. 2004, 2005).

In relation to the theories underpinning the study, the findings support Anthony et al.'s (1999) model of malnutrition in individuals with CF which suggests that certain individual psychosocial factors can influence the development of eating difficulties.

Furthermore, concepts identified in general ED models such as Fairburn et al. (2003) transdiagnostic model are relevant to the CF population as highlighted by the findings of the study.

### 4.2 Clinical Implications

Overall this study highlights the importance of working with individuals with CF to explore their body image attitudes and coping styles as the findings indicate that there is a relationship between these variables and eating behaviours and attitudes. It may be useful to address these issues in the more formal context of therapy or possibly the less formal context of support from within the healthcare team. Although the relationship between CF and DEABs remains unclear, the medical and health consequences of weight loss and unhealthy weight control management behaviours and attitudes in individuals with CF are likely to be greater when compared with healthy individuals.

A screening policy within services for DEABs and body image dissatisfaction may be beneficial in promoting the early detection of any difficulties. Considering the continuum of DEABs to eating disorders (Catterin & Thompson, 1994), some authors have recommended screening for DEABs as part of the routine annual CF nutrition assessment (Bryon et al. 2008). Screening for body image dissatisfaction may be also important as CF may affect the amount of attention paid to the body. A condition such as CF may impact on people's perception of bodily function, sensation, pleasure, competence and safety (Pruzinsky, 2004).

Although DEABs may need to be formally assessed, weight loss or inadequate weight gain may initially need to be assessed within the context of the CF disease process, with the differential diagnosis considering CF-related diabetes, pulmonary exacerbation, hyperthyroidism, inflammatory bowel disease or celiac disease (Shearer & Bryon, 2004) before concluding that an individual is experiencing eating difficulties.

If AN or BN or significant DEABs are identified and diagnosed the individual will most likely require a referral to specialist professionals skilled in the treatment of eating disorders (Bryon et al. 2008). Collaborative working would be required between the nutritionists, medics and clinical psychologists to support the individual in an effective, holistic and beneficial manner.

It would seem that all the treatments (e.g. Cognitive Behaviour Therapy [CBT] and Cognitive Analytic Therapy [CAT]) available to the general population with eating

difficulties would be mostly transferable to individuals with CF; however, these may need to be adapted in order to incorporate the more specific aspects of the disease.

Reveler and Fairburn (1992) have examined the treatment of BN with CBT in individuals with diabetes mellitus. They concluded that CBT can be successfully adapted for the treatment of this population and that improvements can be seen in eating behaviours and glycaemic control. Reveler and Fairburn (1989) also highlight a case study of an individual with both AN and diabetes. CBT was used as a treatment approach and the intervention was concluded to be successful. The authors highlighted some of the modifications to the therapy which included self-monitoring of diabetic regimen behaviours, attention to the adequacy of glycaemic control, information regarding insulin and cognitive restructuring addressing diabetes related thoughts. It may be that some of these adaptations are transferable to the CF population.

Very few studies have examined specific treatments addressing emotions, eating attitudes and behaviours and coping styles with the CF population. However, studies of populations with other illnesses may offer insight into approaches that may be beneficial to individuals with CF. For example, Fawzy et al.'s (1993) study concerned survival in people with malignant melanoma and their findings indicated that a psychological intervention incorporating aspects of coping predicted better survival for the patients at a 6-year follow up.

Hains, Davies, Behrens, Freeman and Biller (2001) have examined CBT for changing coping responses in four individuals with CF. They reported that one individual started to

use a more helpful coping strategy more by the end of treatment. Although, only a very small sample and providing a limited evidence-base, the study offers a useful introduction into the potential use of CBT for supporting individuals in developing more adaptive coping strategies.

### 4.3 Strengths and Limitations

This study has a number of strengths. It is the first study to explore factors that may be related to the development of DEABs in people with CF and the findings suggest that factors such as coping styles and body image may be important in the development and maintenance of DEABs in individuals with CF.

A further strength of the study was the incorporation of measures that were developed specifically for the CF population in comparison to previous research that has used more generic measures developed for the general population. In particular the use of a CFEAB; this was particularly important as the main critique of previous research has identified that measures developed for the general population are not appropriate for individuals with CF. The EAT identified little variance in the CF population in this study in comparison to the CFEAB which was able to identify much more variance and a wider range of scores.

Much of the previous research has been conducted on younger samples exploring eating attitudes and behaviours. This study used a mostly adult population, with a wider range of

ages. Advances in medicine have extended the life expectancy of individuals with CF such that over 50% of newly diagnosed individuals will live into their thirties (Mador & Smith, 1988; Palmer & Boisen, 2002). Therefore, this study offers useful insight into the difficulties experienced by adults with CF.

Although it can be concluded that the study is of clinical and theoretical importance, several limitations need to be considered. Unfortunately, a general study of this nature could not determine the prevalence of eating disorders or disturbed body image in individuals with CF. Furthermore, the relatively small sample size may have made it difficult to detect the full extent of DEABs within the CF population.

A cross-sectional measurement limits the ability to draw firm conclusions about the sequence of the relationship between the variables. This paper proposed that coping styles and body image influence eating attitudes and behaviours, however, it is equally plausible that eating behaviours and attitudes could influence body image satisfaction and coping styles. Similarly there may be other factors that influence eating attitudes and behaviours for example, family context, parental views on diet, weight, and exercise or mood disturbances that may help to identify individuals who could be at risk of developing DEABs or eating disorders (Anthony et al.1999).

The sample was relatively homogenous and care must be taken in generalising these results as the majority of the sample described their ethnic background as 'White –UK'. This reflects the increased prevalence of CF in the Caucasian population (Shearer &

Bryon, 2004); however, the results may not be generalizable to individuals with CF from other ethnic or socio-cultural backgrounds.

Although offering insight into the difficulties experienced by adults with CF, the small number of adolescents in the current study should be considered as a possible limitation. Previous research has highlighted that adolescence is the time period when individuals are most likely to develop DEABs (Garfinkel et al., 1995; Striegel-Moore et al., 2005). There may have also been a selection bias in the study as individuals with eating disorders may have declined to participate due to fears associated with completing the measures and being approached by a clinical psychologist.

The use of self-report measures has both strengths and limitations. Questionnaires have the advantage of being easy to administer, with very little burden to the respondent. A strength of the use of questionnaires over the use of an interview is that they may identify attitudes and behaviours that an individual would not feel comfortable disclosing to an interviewer.

There are also some limitations of the measures used. Although a clinically useful measure it is important to highlight that the CFEAB is not a validated measure at this time and so caution has to be taken in interpreting the findings of the current study. The sensitivity and specificity of the EAT is also of concern because it has been reported to have a high false positive rate (Mintz, O'Halloran, Mullholland & Schneider, 1997). The EAT has been found to report higher estimated rates of eating disorder psychopathology in research with individuals with type 1 diabetes (Crow, Keel & Kendall, 1998). This is

possibly due to the *dieting* scale which focuses on dietary concerns and individuals with diabetes and CF have dietary management concerns and thus would be expected to score higher on this scale.

The FRS has been used extensively in research in the general population. However, the pictures may not be representative of the figures of people with CF. The images are also hand drawn images and it may be that the study could have use more accurate photographic realistic life figures that are now available in the research such as Truby and Paxton (2001).

Although the study aimed to explore gender differences, the measures seemed to be more focused on female concerns. It is disappointing that there was no exploration of increasing muscle tone and the use of steroids in the measures used in the current study which may have provided further evidence for the gender differences in individuals with CF.

The study has presumed that the use of avoidance and distraction are unhelpful coping styles. However, previous research (Abbott et al. 2001) has looked at the links between coping styles and QoL and identified that avoidance coping did not influence QoL and therefore implying that this seems to be an effective way of maintaining psychological health for some individuals. By addressing this coping style a clinician could unintentionally cause more psychological distress to an individual. Therefore, rather than thinking in terms of helpful versus unhelpful coping strategies, it may be more beneficial to think about which coping strategies are adaptive or maladaptive.

#### 4.4 Directions for Future Research

Despite the limitations identified this study adds valuable evidence that may be important in understanding the factors that are related to DEABs. Future research would benefit from further investigation into the other factors such as depression and family factors that may also be important in the development of DEABs. Overall future research with the CF population would benefit from improved methodology, such as larger samples therefore enabling more sophisticated analysis.

It may be that prospective or longitudinal designs could offer more opportunity to understand the sequence of factors important in the development of eating attitudes and behaviours in individuals with CF. It would be of significant clinical interest to explore whether children presenting with problematic meal time behaviours (Steinhausen & Schindler, 1981) later develop eating difficulties as they transition through the various life cycles into adulthood.

Further research is warranted in this area in particular research needs to explore whether there is a trade-off between body image and treatment adherence, in particular dietary management. As indicated by the current and previous research (Abbott et al. 2000; Willis et al. 2001) it seems females are happy with their slim figures, therefore it would be beneficial to explore whether females with CF do exploit their treatment regimens to remain slim. This may offer further explanation for the differing survival rates of the different genders (Australian Cystic Fibrosis Association, 1994; Dodge et al. 1993). CF-created low weight may be perceived as ideal in a society focusing on slimness; however,

this may lead to individuals compromising their health status by not adhering to dietary advice or utilising other aspects of treatment to maintain their low weight.

Evaluation, characterisation and classification of DEABs in individuals with CF holds clinical importance. Focusing on the identified gaps in future research of DEABs in this population could improve clinical care for this serious comorbid condition. It is therefore clinically important to identify those at risk of developing DEABs.

#### 5.0 Conclusion

This study is a useful addition to the limited empirical literature on eating attitudes and behaviours in people with CF. It supports existing evidence that the CF population present with DEABs and highlights two important variables that are related to DEABs. DEABs seem to be associated with certain negative and avoidant coping strategies and body image dissatisfaction. Because these factors could be important in the onset and progression of eating disorders, it is essential they are addressed in the process of a multidisciplinary diagnostic and treatment procedure.

Psychological interventions may be beneficial for individuals with CF and DEABs, especially due to the potential significant health implications if these are not addressed appropriately. The role of the clinical psychologist in the CF support team is necessary as suggested by Oxley and Webb (2005).

Further psychological research is desperately warranted in order to fully understand the complex factors that contribute to people with CF developing DEABs and generating evidence-based interventions to address these issues.

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# **Appendices**

**Appendix A**: Participant Invitation letter.



**University Hospitals NHS Trust** 

Southampton CF Service Southampton General Hospital Tremona Road Southampton Hampshire SO16 6YD



Louise Melhuish Trainee Clinical Psychologist Direct tel: +44 (0)23 80796140 email: lsm1g09@soton.ac.uk

Dear

RE: Eating Attitudes and Behavior Research

We are writing to invite you to participate in a piece of research that is being carried out in the Southampton Regional Cystic Fibrosis Service. Please find enclosed an information sheet providing more detail about the research and what it would entail.

At your next appointment at the Cystic Fibrosis Clinic, a member of the research team will be able to go through the research with you in more detail and discuss whether you would like to take part.

Thank you for taking the time to consider taking part in the research.

Many thanks,

Louise Melhuish Trainee Clinical Psychologist Under the supervision of Dr Alison Pearce, Clinical Psychologist

### **Appendix B**: Parent Invitation Letter



**University Hospitals NHS Trust** 

Southampton CF Service Southampton General Hospital Tremona Road Southampton Hampshire SO16 6YD



Louise Melhuish Trainee Clinical Psychologist Direct tel: +44 (0)23 80796140 email: lsm1g09@soton.ac.uk

Dear (young person and parents),

RE: Eating Attitudes and Behavior Research

We are writing to invite you and your son/daughter to take part in a research study.

We have enclosed an information sheet for your son/daughter and a separate sheet for you. This lets you and your son/daughter know more about the research and will help you to decide whether you and they would like to take part.

If you would like to take part, a member of the research team will be available to talk to you and your son/daughter at your next clinic appointment. They will be able to answer any questions that you might have.

Thank you for taking the time to consider taking part in the research.

Many thanks,

Louise Melhuish Trainee Clinical Psychologist Under the supervision of Dr Alison Pearce, Clinical Psychologist Appendix C: Adult Information Sheet.



**University Hospitals NHS Trust** 

Southampton CF Service
Southampton General Hospital
Tremona Road
Southampton
Hampshire
SO16 6YD



Louise Melhuish Trainee Clinical Psychologist Direct tel: +44 (0)23 80796140

email: lsm1g09@soton.ac.uk

# Participant Information Sheet

Project Title (Full) Eating Behaviour and Attitudes in females and males with Cystic Fibrosis.

The Role of Body Image and Coping Styles

We would like to invite you to take part in a research study. It aims to explore how people's body image and style of coping influences their attitudes towards eating and how they eat.

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

One of our team will be available to discuss the information sheet with you at your next clinic appointment and answer any questions that you may have.

Thank you for reading this.

#### What is the purpose of the research?

At differing times in their lives many people with Cystic Fibrosis (CF) find it difficult to maintain weight and a good nutritional status. It is thought that this is due to many factors. Maintaining a healthy weight has been shown to be important in maintaining lung function and reducing chest infections. Therefore, CF healthcare teams are keen to help people with manage their weight. To help people with Cystic Fibrosis manage their weight, it is important to understand what factors may contribute to people's differing attitudes towards eating and how they eat.

There has been little research trying to understand how peoples' perception of their body image and their coping styles influence their attitudes towards eating and how they eat. This is why this study is being done. The project should take approximately a year to complete, although you will only have to meet a member of the research team once.

#### Why have I been chosen to take part?

You have been chosen to take part because you have CF and are aged over 11 years. The study will include at least 108 people and eligible participants are being identified from CF clinic databases.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you are interested in taking part, we will describe the study when we meet you at your clinic visit and go through this information sheet. You will be told about the research in more detail and given the opportunity to ask any questions.

If you decide to take part, we will ask you to sign a consent form. You are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

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

If you agree to take part in the study, you will be asked to complete the study questionnaires and some health information will be collected at the same time. Your consent, unless you choose to withdraw it, shall remain in effect until the end of the research study. You will be asked to complete six short questionnaires which ask about your attitudes to eating, your coping styles, your general wellbeing and how you view your body image.

To complete all of these questionnaires will take a maximum of 45 minutes. You have a choice as how to complete these. You can complete them before or after your clinic appointment and leave them with a member of staff in an envelope to ensure confidentiality, you can take the questionnaires home with a stamped addressed envelope and post them back to the research team or you can complete them online. If you have any queries about the questionnaires, a member of the research team will be able to offer assistance either in person or by telephone.

As part of the research, we will also access some information about your health (i.e. height, weight and forced expired volume) from your medical notes. This will help us look at how your responses on the questionnaires may be related to other information about health.

#### What about expenses and payments?

It will not cost you anything to take part in the study. If you decide to take part, you can complete the questionnaires during routine visits or at home via the internet. Therefore, research participants are not paid.

#### What are the possible disadvantages of taking part?

Some questions in this study may be considered sensitive, may be difficult to answer or may cause uncomfortable feelings. You can refuse to answer any of these questions or withdraw from the study. You can also ask to speak to Dr Alison Pearce, Principal Researcher and Clinical Psychologist, if you are concerned about any issues that are raised by the questions. Together you can discuss possible options to support you. If you are having lots of difficulties with your eating as indicated by your responses to the Eating Attitudes Questionnaire (EAT), you can decide whether you would like to be informed of this or not. We will ask you to sign the section on the consent form agreeing that you would like Dr Alison Pearce to contact you and your CF team to discuss this and possible options for support.

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

If you agree to take part in the study, we cannot promise that the study will help you. However, the information that we get from this study will help us better understand people's attitudes towards eating and how they eat. Additionally you might find the questionnaires help you understand some of your own eating behaviours and attitudes. You may wish to discuss these with your family, friends or CF team.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you

might suffer will be addressed. Please raise your concerns in the first instance with to the Chief

Investigator, Louise Melhuish by email <a href="mailto:lsm1g09@soton.ac.uk">lsm1g09@soton.ac.uk</a> or the Principal Investigator, Dr

Alison Pearce on 023 80796801, who will try an address any of your concerns. Full contact details

of both researchers are at the end of this information sheet.

If you wish to make a more formal complaint, please contact the hospital's Patient Advice and

Liaison Service (available 9 am to 4.30 pm Monday to Friday, out of hours there is an answer

Email: PALS@suht.swest.nhs.uk

Tel: 023 8079 8498

phone).

**PALS** 

C Level Centre Block

C Level Centre Block

Mailpoint 81

Southampton General Hospital

Tremona Road

Southampton

SO16 6YD

If you have any general questions about your rights as a research participant, you can call the

INVOLVE on 023 80651 088. More details about INVOLVE can be found under the section 'What

could I do to help researchers use my own experience more when they are planning their next

project?'

Which insurance provisions are in place?

In the event that something does go wrong and you are harmed during the research and this is

due to someone's negligence then you may have grounds for a legal action for compensation

against the University of Southampton but you may have to pay your legal costs. As the Chief

Investigator is a student of the University of Southampton, additional professional indemnity and

clinical investigation insurance is in place.

Will my taking part be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in

confidence. If you agree to take part, all information which is collected about you during the

171

EATING BEHAVIOUR AND ATTITUDES IN INDIVIDUALS WITH CYSTIC FIBROSIS

course of the research will be kept strictly confidential and stored securely. If you are having lots

of difficulties with your eating as indicated by your responses to the Eating Attitudes

Questionnaire (EAT), you can decide whether you would like to be informed of this or not. We will

ask you to sign the section on the consent form agreeing that you would like Dr Alison Pearce to

contact you and your CF team to discuss this and possible options for support.

Once scored, the questionnaires will be individually numbered and coded so that your data will not

have any identifying details. The information collected will be kept in locked cabinets at

Southampton General Hospital. The names associated with the identifying numbers will be kept in

a locked cabinet separate from the questionnaires. Any public report of the study's findings will

contain no identifying details about participants.

What will happen to the results of the study?

The information and data collected during the study will be written up as part of a Clinical

Psychology doctoral thesis for the researcher and will be published in a medical or psychology

journal after June 2012. The results may also be presented at a conference for professionals who

work with people with CF. A brief summary from the study will also be found on the Southampton Regional Adult and Child CF Units' web site with references to the published papers so that you

can access them if you wish.

Who is organising and funding the research?

The University of Southampton is organising and funding the research.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics

Committee, to protect your interests. This study has been reviewed by the National Research

Ethics Committee South Central -Southampton and given a favourable opinion.

Where can I find out more about research in general?

There is currently no single organisation for this in the UK; however you may contact the Research

& Development (R&D) Department of your local hospital or University which may be able to guide

you further. Alternatively you could contact:

The Cystic Fibrosis Trust

Support helpline: 0300 373 1000

172

EATING BEHAVIOUR AND ATTITUDES IN INDIVIDUALS WITH CYSTIC FIBROSIS

Or email: enquiries@cftrust.org.uk

What could I do to help researchers use my own experience more when they are planning

their next project?

Do you want to get more involved and help researchers improve future project ideas and research information leaflets? Please contact "People in Research - Opportunities for public involvement in research" http://www.peopleinresearch.org/. If you would like to help, you can also contact INVOLVE which is a national advisory group, funded by the National Institute for Health Research (NIHR). Its role is to support and promote active public involvement in NHS, public health and social care research. http://www.invo.org.uk/ or Wessex House, Upper Market Street, Eastleigh,

Hampshire, SO50 9FD, Telephone: 02380 651088 Email admin@invo.org.uk

Thank you for your time.

**Contact Details:** 

Louise Melhuish, Trainee Clinical Psychologist

email:lsm1g09@soton.ac.uk

Dr Alison Pearce - Project Supervisor, Clinical Psychologist

Chartered Clinical Psychologist

Direct tel: +44 (0)23 80796801

Direct fax: +44 (0)23 80794961

173

#### **Appendix D**: Young Person Information Sheet







**University Hospitals NHS Trust** 

Southampton CF Service Southampton General Hospital

Tremona Road

Southampton

Hampshire

SO16 6YD

Louise Melhuish Trainee Clinical Psychologist Direct tel: +44 (0)23 80796140

email: lsm1q09@soton.ac.uk

# Participant Information Sheet 11 - 16 years of age

Project Title (Full) Eating Behaviour and Attitudes in People with Cystic Fibrosis. The Role of Body Image and Coping Styles

You are being invited to take part in a research project. This sheet will tell you a bit about the research and why we are doing it. You can ask somebody from the CF team, your parents, or any of the researchers, if you have any questions, or if there is anything that you do not understand.

If you are interested in the study, one of the researchers will go through the information sheet with you at your next clinic appointment and answer any questions that you have. Thank you for reading this.

Why are we doing this research?

Some people with CF find it difficult to stay at a healthy weight. This research project hopes to find out more about the way that people eat and think about food. We also want to find out if how you deal with things and see your body may effect how you eat.

#### Why have I been invited to take part?

You have been asked to take part because you have Cystic Fibrosis and are aged 11 years or over.

#### Do I have to take part?

It is up to you and your parents to decide whether or not you wish to take part. If you would like to, we will be available for you to speak to at your next clinic visit. We will describe the study to you and go through this information sheet with you. If you agree to take part you or your parents can ask for you to stop taking part at any time, without giving a reason. If you don't want to take part or stop taking part this would not affect the care you receive from the CF team.

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

If you decide to take part, the researcher will ask your parents to sign a consent form (because you are under 16 years). You will also be asked to sign a form to say that you want to take part too.

You will be asked to complete six short questionnaires. These ask about your thoughts about eating, how you deal with things, your general health and how you view your body. To complete all of the questionnaires will take no more than 45 minutes. If you are aged between 11 and 13 years old your parents will be asked to completed one questionnaire.

You have a choice about how to complete these. You can fill them in before or after your clinic appointment and leave them with a member of staff in an envelope, you can take the questionnaires home and post them back to the research team or you can complete them online.

We will also ask you and your parents to let us use information about your health (i.e. height, weight and forced expired volume).

# What if there is a problem?

If you have a concern about any part of this study then you can talk to your parents, anyone in the CF team or the researchers. They will do their best to answer your questions and sort out any problems.

#### Will anyone else know I'm doing this?

If your answers show us that you may be finding it difficult to eat and your parents have agreed that they would like to know this, we will talk to somebody in your CF Team and they will contact you and your parents to discuss this. They will make sure that you get some help with this if you want it.

Once scored all the questionnaires will be given a number and will not have your name on them. The questionnaires will be kept in a locked cabinet that can only be accessed by the researchers.

#### What are the possible disadvantages and risks of taking part?

Some of the questions may be difficult for you to answer and may make you worry or feel sad. You do not have to answer these questions if you don't want to. The questionnaires may also show us that you are finding it difficult to eat.

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

Taking part may help us understand more about the way that people with CF eat and think about food. This information may help CF teams support people with managing their weight. However, there are unlikely to be any direct benefits to you directly.

#### Where can I get more information?

We know that young people want different amounts of information depending on how they are feeling, how old they are and many other reasons, so if you want to know more then please ask you parents or your CF team.

177

Thank you very much for reading this.

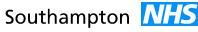
#### **Contact details:**

# Louise Melhuish Trainee Clinical Psychologist

Direct tel: +44 (0)23 8079 6801 email:lsm1g09@soton.ac.uk

# Dr Alison Pearce - Project Supervisor, Clinical Psychologist

Chartered Clinical Psychologist Direct tel: +44 (0)23 8079 6801 Direct fax: +44 (0)23 8079 4961 **Appendix E**: Parent/Legal Guardian Information Sheet.







Louise Melhuish Trainee Clinical Psychologist Direct tel: +44 (0)23 80796140

email: <a href="mailto:lsm1g09@soton.ac.uk">lsm1g09@soton.ac.uk</a>

Southampton CF Service Southampton General Hospital Tremona Road

Hampshire

Southampton

SO16 6YD

# Parent/Legal Guardian Information Sheet

Project Title (Full) Eating Behaviour and Attitudes in females and males with Cystic Fibrosis.

The Role of Body Image and Coping Styles

We would like to invite you and your son/daughter to take part in a research study. It aims to explore how people's body image and style of coping influences their attitudes towards eating and how they eat.

Your son/daughter is being invited to take part in a research study. Before you decide whether you agree to you son/daughter participating it is important for you to understand why the research is being done and what it will involve for your son/daughter. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. One of our team will be available to discuss the information sheet with you and your son/daughter at your next clinic appointment and answer any questions that you may have.

Thank you for reading this.

#### What is the purpose of the research?

At differing times in their lives many people with Cystic Fibrosis (CF) find it difficult to maintain weight and a good nutritional status. It is thought that this is due to many factors. Maintaining a healthy weight has been shown to be important in maintaining lung function and reducing chest infections. Therefore, CF healthcare teams are keen to help people with manage their weight. To help people with Cystic Fibrosis manage their weight, it is important to understand what factors may contribute to people's differing attitudes towards eating and how they eat.

There has been little research trying to understand how peoples' perception of their body image and their coping styles influence their attitudes to eating and how they eat. This is why this study is being done. The project should take approximately a year to complete, although your son/daughter will only have to meet a member of the research team once.

#### Why has your son/daughter been chosen to take part?

Your son/daughter has been chosen to take part because they have CF and are aged 11 years or over. The study will include at least 108 people and eligible participants are being identified from CF clinic databases.

#### Do they have to take part?

It is up to you to decide whether or not your son/daughter takes part. If you and your son/daughter are interested in taking part, we will describe the study when we meet you and your son/daughter at your clinic visit and go through this information sheet. You will be told about the research in more detail and given the opportunity to ask any questions.

If you decide to agree to your son/daughter taking part, we will give you this information sheet and ask you to sign a consent form and for your son/daughter to sign an assent form. Your son/daughter is free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your son/daughter receives.

#### What will happen to your son/daughter if they take part?

If you and your son/daughter agree to take part in the study, your son/daughter will be asked to complete the study questionnaires and some health information will be collected at the same time.

Your consent and your son/daughter's assent, unless you choose to withdraw it, shall remain in effect until the end of the research study.

Your son/daughter will be asked to complete six short questionnaires which ask about their attitudes towards eating, their coping styles, their general wellbeing and how they view their body image. If you child is aged between 11 and 13 years old you will also be asked to complete one questionnaire. The researcher will be happy to show you these questionnaires to help you decide if you are happy for your son/daughter to complete them.

To complete all of these questionnaires will take a maximum of 45 minutes. You and your son/daughter have a choice as how to complete these. You and your son/daughter can complete them before or after your clinic appointment and leave them with a member of staff in an envelope to ensure confidentiality, you can take the questionnaires home with a stamped addressed envelope and post them back to the research team or you and your son/daughter can complete them online. If you or your son/daughter has any queries about the questionnaires, a member of the research team will be able to offer assistance either in person or by telephone.

As part of the research, we will also access some information about your son/daughter's health (i.e. height, weight and forced expired volume) from their medical notes. This will help us look at how their responses on the questionnaires may be related to other information about health.

## What about expenses and payments?

It will not cost you or your son/daughter anything to take part in the study. If they decide to take part, they can complete the questionnaires during routine visits or at home via the internet. Therefore, research participants are not paid.

### What are the possible disadvantages of taking part?

Some questions in this study may be considered sensitive, may be difficult to answer or may cause uncomfortable feelings. Your son/daughter can refuse to answer any of these questions or withdraw from the study. Your son/daughter or you can also ask to speak to Dr Alison Pearce, Principal Researcher and Clinical Psychologist, if you or they are concerned about any issues that are raised by the questions. Together you can discuss possible options to support your son/daughter. If your son or daughter is having lots of difficulties with their eating as indicated by their responses to the Eating Attitudes Questionnaire (EAT), you can decide whether you would like to be informed of this or not. We will ask you to sign the section on the consent form agreeing

that you would like Dr Alison Pearce to contact you, your son/daughter and your CF team to discuss this and possible options for support.

What are the possible benefits of taking part?

If you and your son/daughter agree to take part in the study, we cannot promise that the study will help them. However, the information that we get from this study will help us better understand people's attitudes towards eating and how they eat. Additionally your son/daughter might find the questionnaires help them understand some of their own eating behaviours and attitudes. They may wish to discuss these with their family, friends or CF team.

What if there is a problem?

Any complaint about the way you or your son/daughter have been dealt with during the study or any possible harm they might suffer will be addressed. Please raise your concerns in the first instance with to the Chief Investigator Louise Melhuish by email <a href="mailto:lsm1g09@soton.ac.uk">lsm1g09@soton.ac.uk</a> or the Principal Investigator, Dr Alison Pearce on 023 80796801, who will try an address any of your concerns. Full contact details of both researchers are at the end of this information sheet.

If you wish to make a more formal complaint, please contact the hospital's Patient Advice and Liaison Service (available 9 am to 4.30 pm Monday to Friday, out of hours there is an answer phone).

PALS
C Level Centre Block
Mailpoint 81
Southampton General Hospital
Tremona Road
Southampton
SO16 6YD

Email: PALS@suht.swest.nhs.uk

Tel: 023 8079 8498

If you have any general questions about your rights as a research participant, you can call the INVOLVE on 023 80651 088. More details about INVOLVE can be found under the section 'What could I do to help researchers use my own experience more when they are planning their next project?'.

181

### Which insurance provisions are in place?

In the event that something does go wrong and your son/daughter is harmed during the research and this is due to someone's negligence then you and your son/daughter may have grounds for a legal action for compensation against the University of Southampton but you may have to pay your legal costs. As the Chief Investigator is a student of the University of Southampton, additional professional indemnity and clinical investigation insurance is in place.

## Will my taking part be kept confidential?

We will follow ethical and legal practice and all information about your son/daughter will be handled in confidence. If you agree to you son/daughter taking part, all information which is collected about your son/daughter during the course of the research will be kept strictly confidential and stored securely.

If your son/daughter is having lots of difficulties with their eating as indicated by their responses to the Eating Attitudes Questionnaire (EAT), you can decide whether you would like to be informed of this or not. We will ask you to sign the section on the consent form agreeing that you would like Dr Alison Pearce to contact you, your son/daughter and your CF team to discuss this and possible options for support.

Once scored, the questionnaires will be individually numbered and coded so that your son/daughter's data will not have any identifying details. The information collected will be kept in locked cabinets at Southampton General Hospital. The names associated with the identifying numbers will be kept in a locked cabinet separate from the questionnaires. Any public report of the study's findings will contain no identifying details about participants.

## What will happen to the results of the study?

The information and data collected during the study will be written up as part of a Clinical Psychology doctoral thesis for the researcher and will be published in a medical or psychology journal after June 2012. The results may also be presented at a conference for professionals who work with people with CF. A brief summary from the study will also be found on the Southampton Regional Adult and Child CF Units' web site with references to the published papers so that you can access them if you wish.

### Who is organising and funding the research?

EATING BEHAVIOUR AND ATTITUDES IN INDIVIDUALS WITH CYSTIC FIBROSIS

The University of Southampton is organising and funding the research.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your son/daughter's interests. This study has been reviewed by the

National Research Ethics Committee South Central -Southampton and given a favourable opinion.

Where can I find out more about research in general?

There is currently no single organisation for this in the UK; however you may contact the Research & Development (R&D) Department of your local hospital or University which may be able to guide

you further. Alternatively you could contact:

The Cystic Fibrosis Trust

Support helpline: 0300 373 1000

Or email: enquiries@cftrust.org.uk

What could I do to help researchers use my own experience more when they are planning

their next project?

Do you or your son/daughter want to get more involved and help researchers improve future project ideas and research information leaflets? Please contact "People in Research - Opportunities for public involvement in research" http://www.peopleinresearch.org/. If you would like to help, you can also contact INVOLVE which is a national advisory group, funded by the National Institute for Health Research (NIHR). Its role is to support and promote active public involvement in NHS, public health and social care research. http://www.invo.org.uk/ or Wessex House, Upper Market Street, Eastleigh, Hampshire, SO50 9FD, Telephone: 02380 651088 Email admin@invo.org.uk

Thank you for your time.

**Contact Details:** 

Louise Melhuish, Trainee Clinical Psychologist

email:lsm1g09@soton.ac.uk

Dr Alison Pearce - Project Supervisor, Clinical Psychologist

Chartered Clinical Psychologist

Direct tel: +44 (0)23 80796801

Direct fax: +44 (0)23 80794961

183

## **Appendix F**: Demographics Form

П

African

Other

Caribbean

**About You** Please answer the following questions about yourself. Please fill- in the information or tick the box indicating your answer. What is your gender? ☐ Male ☐ Female Date of Birth: Age: Height: Weight: What is your current marital status? Single/never married Married Widowed Divorced Separated Remarried With a partner Which of the following best describes your racial background? White - UK White - Other Indian/Pakistani Chinese/Asian 

is the highest level of education you have completed?
Some secondary school or less
GCSEs/O-levels
A/As levels
Other higher education
University degree
Professional qualification or post-graduate study
of the following best describes your current work or school status?
Attending school outside the home
Taking educational courses at home
Seeking work
Working full or part time (either outside the home or at a home-based business)
Full time homemaker
Not attending school or work due to my health
Not working for other reasons

# Appendix G: Cystic Fibrosis Eating Attitude & Behaviour (CFEAB) Questionnaire.

	Item	Never	Rarely	Sometimes	Often	Always	Score
1	I enjoy eating.						
2	I want to be thinner.						
3	I cut down on food to lose weight.						
4	I find it hard to gain weight.						
5	I don't feel like eating when others tell me to eat.						
6	I am afraid of becoming fat.						
7	Even if I feel unwell, I try to eat something.						
8	The thought of eating food makes me feel worried.						
9	I feel full quickly.						
10	So I won't gain weight, I deliberately don't take my enzymes.						
11	So I won't gain weight, I deliberately don't take my insulin.						
12	So I won't gain weight, I deliberately don't take my extra feeds or supplements.						
13	I have a good appetite for food.						
14	I would like to eat less to lose weight.						
15	I spend time wishing I weighed more.						
16	I make myself vomit (sick) after I eat to control my weight.						
17	I feel I am too fat.						
18	I exercise as a way to lose weight.						
19	I feel I need to be thin to be happy with myself.						
20	I am put off eating because my CF makes me feel sick.						
21	Gaining weight makes me feel happy.						
22	I eat low fat or low sugar foods so I won't gain weight.						
23	I pretend to others that I have eaten.						
24	I feel guilty after eating.						
							Total

Total

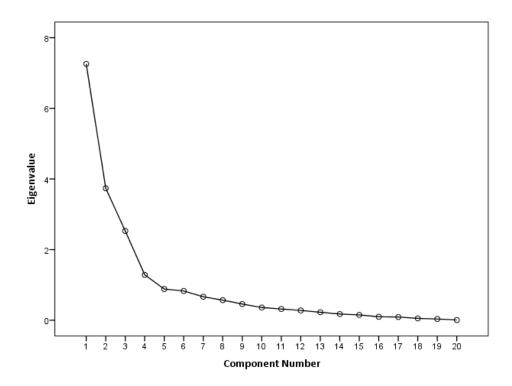
Appendix H: Principal Component Analysis of the CFEAB

Due to the CFEAB being an unpublished and only recently validated measure (Randlesome and Bryon, 2011), a principal component analysis (PCA) was conducted on the 20 (4 items were removed, three items as advised by the original author and see below for the explanation of the removal of the fourth item) items of the CFEAB with orthogonal rotation (varimax). An oblique rotation was considered but as all of the correlations were below 0.2 it was decided that a PCA would be more appropriate.

The Kaiser-Meyer-Olkin (KMO) measure verified the sampling adequacy for the analysis, the KMO value for the CFEAB data was 0.79, which is well above the acceptable limit of 0.5 (Field, 2009). Bartlett's test of sphericity is a sensitive test of the null hypothesis that there are no correlations between the variables in the population. The test should be significant if the data is suitable for factor analysis, as it was in the CFEAB data set  $(X^2 (190) = 1991.80, P < .001.$ 

The scree plot was slightly ambiguous and these in combination with the eigenvalues were examined to determine how many factors to extract. The analysis identified four eigenvalues with values above 1; however, there appeared to be only three factors that were above the point of inflexion on the scree plot (see figure below). Since the fourth eigenvalue was only a little above 1 and accounted for a maximum of 6% of the variance in the data set, it was decided to only extract three factors. Furthermore, the original author suggested three factors.

Figure . Scree Plot.



In the first round of PCA, CFEAB item 23 ('I pretend to others that I have eaten') was a complex variable loading onto Factors 2 and 3 with loadings greater than 0.4. As Tabachnick and Fidell (2007) highlight, it is usually best to avoid such complex variables since they make interpretation of factors more ambiguous. This item was therefore removed from the CFEAB measure. The factor structure that emerged from the PCA is displayed in Table below.

Table. Factor loading matrix, eigenvalues and amount of variance for items loading onto each factor.

CFEAB	Factor 1	Factor 2	Factor 3
1. I enjoy eating.			.81

	1		
2. I want to be thinner.	.89		
3. I cut down on food to lose weight.	.82		
6. I am afraid of	.78		
becoming fat.			
8. The thought of eating			.64
food makes me feel			
worried.			
9. I feel full quickly.			.66
10. So I won't gain		.98	
weight, I deliberately			
don't take my enzymes.		0.5	
11. So I won't gain		.95	
weight, I deliberately don't take my insulin.			
12. So I won't gain		.96	
weight, I deliberately		.,,0	
don't take my extra feeds			
or supplements.			
13. I have a good appetite			.78
for food.			
14. I would like to eat	.87		
less to lose weight.	.54		
15. I spend time wishing I weighed more.	.54		
16. I make myself vomit		.90	
(sick) after I eat to control		.,,	
my weight.			
17. I feel I am too fat.	.86		
18. I exercise as a way to	.69		
lose weight.			
19. I feel I need to be thin	.68		
to be happy with myself.			7.4
20. I am put off eating because my CF makes me			.74
feel sick.			
21. Gaining weight	.71		
makes me feel happy.			
22. I eat low fat or low	.72		
sugar foods so I won't			
gain weight.			
24. I feel guilty after	.69		
eating.	7.26	2.74	2.52
Eigenvalues	7.26	3.74	2.53
% of Variance	36.29	18.68	12.64

## **Factor Interpretation**

As identified by the original author of the measure the items fell into three distinct factors and the PCA conducted confirmed this. To interpret the extracted factors, the items loading onto each of the factors were examined by the original research team (Randlesome & Bryon, unpublished) for common themes.

### Factor 1

It seemed clear that Factor 1 accessed a number of cognitions and behaviours related to weight loss and the pursuit or value of thinness consistent with a number of the criteria for AN and BN (APA, 1994). Therefore, this factor was named 'Eating Disorders'.

### Factor 2

Factor 2 seemed to access a mix of CF-specific EABs and another EAB that may be related to eating-disordered psychopathology. This factor was named 'CFEAB'.

### Factor 3

It seemed clear that the five items on Factor three were mostly accessing concepts around appetite for food and therefore this factor was named 'Appetite'.

## **Appendix I**: Adult Consent Form.



Southampton University Hospitals NHS Trust

Southampton CF Service Southampton General Hospital Tremona Road Southampton Hampshire . SO16 6YD

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Louise Melhuish Trainee Clinical Psychologist Direct tel: +44 (0)23 80796140 email: lsm1q09@soton.ac.uk

# **INFORMED CONSENT FORM Adult Version**

Title	of study:	Eating Behaviour and Attitudes in People wi The Role of Body Image and Coping Styles.	•
Centr Unive REC	e of Principal Investigator: e/Site number: ersity Study number: 408 approval number: eipant ID:	Louise Melhuish	
	k you for reading the inform part, please read and sign t	ation about our research project. If you would his form.	l like to
PLEA	SE <u>INITIAL</u> THE BOXES IF	YOU AGREE WITH EACH SECTION:	
1.	above study and have bee	n sheet Version 1 dated 26.02.11 for the en given a copy to keep. I have had the e information, ask questions and have had orily.	
2.		cipation is voluntary and that I am free to out giving any reason, without my medical affected.	
3.	that completing the questi	x questionnaires for the study. I understand fonnaires for this research is voluntary and my approval for use of the data at any time.	

I understand that the data collected from this study will be made

confidential and will be securely stored.

5. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from Southampton University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. I understand that the information will be kept confidential.				
6. I understand that some of the questions are of a sensitive nature and I would like Alison Pearce, Clinical Psychologist to contact me if my responses indicate eating difficulties that without intervention or support may impact negatively on my health.				
7.	7. I understand that my GP may be informed of my participation and also if any of the results of questionnaires done as part of the research are important for my health.			
8. I know how to contact the research team if I need to.				
9.	I agree to participate in this study			
Partic	ipant::	Date:	Signature:	
Resea	archer taking consent:	Date:	Signature:	

## **Appendix J**: Young Person Assent Form.



**University Hospitals NHS Trust** 



Eating Behaviour and Attitudes in People with Cystic Fibrosis. The Role of Body Image and Coping Styles.

Southampton CF Service Southampton General Hospital Tremona Road Southampton Hampshire SO16 6YD

Name of Principal Investigator:

Title of study:

Louise Melhuish Trainee Clinical Psychologist Direct tel: +44 (0)23 80796140 email: Ism1q09@soton.ac.uk

# ASSENT FORM Young Person aged 11-15 years

Louise Melhuish

	Study number: 408 val number:		
Young p	erson to circle all they agree with:		
10.	Has somebody explained this research project to y	ou?	Yes /
11.	Do you understand what this project is about?		No Yes / No
12.	Have you asked all the questions you want to ask?		Yes / No
13. Have you had your questions answered in a way you understand?		u	Yes / No
14.	Do you understand it is OK to stop taking part at a	ny time?	Yes / No
15.	Are you happy to take part?		Yes / No
If any an	swers are "no" or you don't want to take part, don'	t sign your r	name!
If you do	want to take part, you can write your name here:		
Your Nai	me:	Date:	

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

## **Appendix K**: Parent/Legal Guardian Consent Form.





Southampton CF Service Southampton General Hospital Tremona Road Southampton Hampshire SO16 6YD Louise Melhuish Trainee Clinical Psychologist Direct tel: +44 (0)23 80796140 email: lsm1g09@soton.ac.uk

# INFORMED CONSENT FORM Parent/Legal Guardian

	га	irent/Legal Guardian	
Title of stu	udy:	Eating Behaviour and Attitudes in People with The Role of Body Image and Coping Styles.	th Cystic Fibrosis.
Centre/Sit University	Principal Investigator: te number: Study number: oval number: t ID:	Louise Melhuish 408 11/SC/0153	
•	<u> </u>	ation about our research project. If you would read and sign this form.	like your
PLEASE <u>I</u>	NITIAL THE BOXES IF	YOU AGREE WITH EACH SECTION:	
6	above study and have b	tion sheet Version 1 dated 26.02.11 for the been given a copy to keep. I have had the the information, ask questions and have had ctorily.	
t	that they are free to with	on/daughter's participation is voluntary and hdraw at any time without giving any reason, are or legal rights being affected.	
t c f	the study. If my child is one questionnaire. I un for this research is volu	ghter to complete the six questionnaires for aged between 11 -13 I agree to complete derstand that completing the questionnaires ntary and that my son/daughter is free to for use of the data at any time.	
19. I	I understand that the da	ata collected from this study will be made	

# confidential and will be securely stored.

20. I understand that relevant sections of my son/daughter's medical notes and data collected during the study may be looked at by individuals from Southampton University, from regulatory authorities or from the NHS Trust, where it is relevant to them taking part in this research. I give permission for these individuals to have access to my son/daughter's records. I understand that the information will be kept confidential.				
21.	21. I understand that some of the questions are of a sensitive nature and I would like Alison Pearce, Clinical Psychologist or a member of the CF team to contact me and my son/daughter if their responses indicate eating difficulties that without intervention or support may impact negatively on my son/daughter's health.			
22.	22. I understand that my son/daughter's GP may be informed of their participation and also if any of the responses of the questionnaires completed as part of the research are important for my son/daughter's health.			
23.	23. I know how to contact the research team if I need to.			
24.	24. I agree to my son/daughter participating in this study			
Parent/Legal Guardian: Date: Signature:				
Resea	archer taking consent:	Date:	Signature:	

## Appendix L: NHS Favourable Opinion Letter



# National Research Ethics Service NRES Committee South Central - Southampton A

Level 3, Block B Whitefriars Lewins Mead Bristol BS1 2NT

Telephone: 0117 342 1381 Facsimile: 0117 342 0445

20 May 2011

Miss Louise Melhuish Trainee Clinical Psychologist Taunton and Somerset NHS Trust Department of Clinical Psychology 34 Bassett Crescent East Highfield, Southampton SO16 7PB

Dear Miss Melhuish

Study title:

Eating behaviour and attitudes in females and males with cystic fibrosis. The role of body image and coping

styles.

**REC** reference:

11/SC/0153

The Research Ethics Committee reviewed the above application at the meeting held on 10 May 2011. Thank you for attending to discuss the study.

### Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

### Ethical review of research sites

NHS Sites

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

### Conditions of the favourable opinion

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

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

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

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

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

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

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

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

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

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation

## Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		07 April 2011
Evidence of insurance or indemnity		29 March 2011
Investigator CV	L. Melhuish	07 April 2011
Investigator CV	C. Brignell	08 April 2011
Letter from Sponsor		31 March 2011
Letter of invitation to participant	1.0	26 February 2011
Letter of invitation to participant	1.0	26 February 2011
Participant Consent Form: CF - Parent/Guardian	1.0	26 February 2011
Participant Consent Form: CF - Young Person	1.0	26 February 2011
Participant Consent Form: CF - Adult	1.0	26 February 2011
Participant Information Sheet: PIS - Parent/Guardian	1.0	26 February 2011
Participant Information Sheet: PIS - Young Person	1.0	26 February 2011
Participant Information Sheet: PIS - Adult	1.0	26 February 2011
Protocol	1.0	15 December 2010
Questionnaire: Questionnaire - Ages 14+		
Questionnaire: Questionnaire - Ages 12 - 13		
Questionnaire: Questionnaire - Ages 11		
Questionnaire: CFEAB Within Questionnaire pack		
REC application		11 April 2011
Referees or other scientific critique report		

#### Issues discussed

- The Committee questioned the online security of the participant when answering the questionnaire. The researcher explained that they had spoken to data protection at the hospital. Participants will have login details of which only the researchers will have access.
- 2. The Committee raised concerns that in 'Cystic Fibrosis Eating Attitude & Behaviour (CFEAB) Questionnaire', questions 10, 11 and 12 might run the risk of introducing incorrect methods of controlling weight. The researcher informed the Committee that the group is already very medically informed of their condition and that they would already be aware of the issues outlined in the questionnaire.
- 3. The Committee pointed out the inconsistency, within the study. It indicates participants should fill out as much of the questionnaire as possible, however at the end of a particular questionnaire it requests all questions are filled in. The research thanked the Committee for pointing this out and affirmed this would be changed.
- 4. The Committee asked the researchers whether they had any questions. The researcher wanted to know whether the Committee approved of the patient information sheet. The Committee expressed appreciation and articulated that it was very informative.

#### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

### Statement of compliance

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

### After ethical review

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

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

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

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

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email <a href="mailto:referencegroup@nres.npsa.nhs.uk">referencegroup@nres.npsa.nhs.uk</a>.

## 11/SC/0153

Please quote this number on all correspondence

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

Yours sincerely

pp

Dr Iain MacIntosh

Email: scsha.SWHRECA@nhs.net

Enclosures: List of na

List of names and professions of members who were present at the

meeting and those who submitted written comments "After ethical review – guidance for researchers"

Copy to:

Hope Howard

Hope Howard, Southampton University Hospital Trust R&D

## Appendix M: R&D Approval Letter.

### Southampton University Hospitals NHS Trust

Please reply to:

Research & Developmen SGH - Level E, Laboratory & Pathology Block, SCBR - MP 138 Southampton University Hospitals NHS

Telephone: 023 8079 4862 Fax: 023 8079 8678 E-mail: hope.howard@suht.swest.nhs.uk

Dr Alison Pearce Adult Cystic Fibrosis Unit C Level, West Wing Mailpoint 76 Southampton General Hospital Southampton SO16 6YD

04 July 2011

Dear Dr Pearce

ID: RHM MED0986

Eating behaviour and attitudes in females and males with cystic fibrosis. The role of body image and coping styles.

#### EudraCT:

Thank you for submitting all the required documentation for Trust R&D approval. I write to inform you that your study has full SUHT R&D approval. Please find attached the Conditions of Trust R&D approval which you are obliged to adhere to.

You are required to keep copies of all your essential documents relating to this study. Please download a copy of the relevant Investigator Site File template from the R&D website: http://tinyurl.com/3xtxv66.

Your project is subject to R&D monitoring and you will be contacted by our office to arrange this.

Please note: A condition of approval is that any changes need to be timeously notified to the R&D office. This includes providing copies of:

- . All NRES substantial amendments and favourable opinions; . All Serious Adverse Events (SAEs);
- NRES Annual Progress Reports; Annual MHRA Safety Reports; NRES End of Study Declaration;
- . Notifications of significant breaches of GCP or protocol

Please quote the above RHM No. on any correspondence with our office.

Should you, or any of your team, require training in any of the policies and procedures required to ensure compliance with the conditions of approval, please refer to the R&D Training website http://tinyurl.com/prkd65 for an up-to-date calendar of training events.

Yours sincerely

populoward

Hope Howard

Research Governance Officer