Journal of Cystic Fibrosis 7 (2008) 437–439

www.elsevier.com/locate/jcf

Distorted body image and anorexia complicating cystic fibrosis in an adolescent

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Received 4 January 2008; received in revised form 14 April 2008; accepted 18 April 2008
Available online 6 June 2008

Abstract

A 15 year old girl with cystic fibrosis has been dieting and losing weight for 2 years. Despite being underweight she aims to lose a further 6 kg to become a "size zero". Her falling weight has been associated with deteriorations in her general health and lung function, which is exacerbated by poor compliance. The situation has been complicated further by her becoming pregnant.

Keywords: Cystic fibrosis; Anorexia; Pregnancy

1. Introduction

It is accepted that patients with cystic fibrosis (CF) can improve their respiratory prognosis by optimising nutrition in order to achieve normal growth patterns [1]. This is achieved by the combination of a high calorie diet, pancreatic enzyme replacement and vitamin supplementation [1,2]. Unfortunately the media driven obsession with super-thin celebrities has contributed to some young people with CF having distorted views on what is an acceptable body image and they choose to be non-compliant with such regimes so that they can lose weight. By doing this they put themselves at risk of suboptimal growth and respiratory deterioration. Although patients with CF can have normal pregnancies, poor nutritional status at conception and inadequate weight gain during pregnancy are associated with poorer outcomes for mother and infant [3,4,5].

2. Case report

A 15 year old girl with CF has had a 2 year history of restricting her food intake and losing weight. She was diagnosed with CF at the age of 4 weeks by sweat test (sweat chloride concentrations: 125, 105, 85 mmol/L) after presenting with failure to thrive. Subsequent investigations revealed her to be pancreatic insufficient and homozygous for the ΔF508 mutation. *Pseudomonas aeruginosa* was first isolated aged 15 months and she was chronically infected at 6 years of age.

At 13 years she started to limit her oral intake to just a few mouthfuls of food at mealtimes and the occasional piece of fruit during the day. She has always denied the use of laxatives or purging after meals. In the 2 years since the dieting started her weight has fallen from 45 to 41.8 kg (25th to 2nd percentile). Her current weight for height is 83.5%. Despite input from the dietician and psychologist she has refused to increase her oral intake or to take oral supplements.

As her weight for height ratio has decreased there has been an associated deterioration in her general health, exacerbated by poor compliance with medications and physiotherapy. She has required four admissions for intravenous antibiotics and complains of constant lethargy. On questioning, she denies feeling any subjective improvement after courses of intravenous antibiotics. She gets short of breath after minimal exertion and her percent predicted FVC and FEV1 have fallen from 92% and 88% 2 years ago to 52% and 53% respectively. (Fig. 1)

The patient does gain weight during hospital admissions but will boast how quickly she will be able to lose it when she goes home and then follows through with this threat. During two

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doi:10.1016/j.jcf.2008.04.003

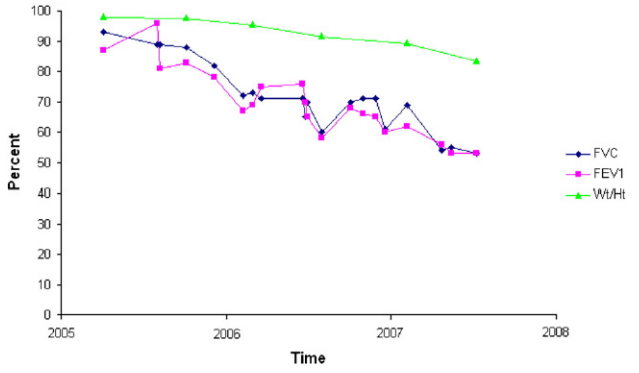

Fig. 1. Graph showing percent wt/ht and percent predicted FVC and FEV1 over the last 2 years.

hospital admissions additional weight gain has been achieved by the patient having overnight naso-gastric feeds, unfortunately this weight was also lost quickly when she returned home. More recently she has refused such feeds.

Discussion with the patient reveals that she has a markedly abnormal body image and despite being underweight views herself as fat. She weighs herself regularly and has repeatedly stated that she wants to lose more weight to become less than 6 stone. By doing this she will emulate her celebrity role models and become a "size zero". Her friends as well as her mother regularly diet and they compare weight loss and eating habits. She associates gaining weight with losing friends and becoming lonely, this fear has become so severe that she becomes low in mood when she does gain weight. She is aware that by continuing to diet she is likely to be shortening her life expectancy but refuses to stop.

There are a number of social factors that are likely to have contributed to her symptoms including the break up of her parent's marriage, a decline in her school attendance and her boyfriend being in trouble with the police on a number of occasions. Family therapy sessions have been organised by the clinical psychologist but the patient is reluctant to engage in these sessions and has not attended on a number of occasions.

At the age of 15 years she became pregnant. The patient and her family were counselled at length regarding the possible risks to herself and the baby due to her CF and particularly her poor nutritional status. After these sessions the patient opted to have a termination of the pregnancy. We continue to try and engage her in psychological and medical support for her condition. She wishes to remain in the paediatric CF clinic for the foreseeable future rather than transferring through our young persons (transition) CF clinic to the adult CF clinic.

3. Discussion

This patient highlights the importance of nutritional status in CF and shows how complex it can be for the CF team to be of help. By combining a high calorie diet with pancreatic enzyme supplementation normal growth patterns can be achieved and this has been shown to improve respiratory function and overall survival [1]. If there is difficulty in achieving good nutrition then further dietary support should be implemented, unfortunately patients with eating disorders are unlikely to comply with such advice. If patients with CF do become malnourished then there is acceleration in their pulmonary deterioration. The mechanism for this is thought to be a related to muscle weakness and an increase in resting energy expenditure [6].

Anorexia is the result of complex interactions between genetics, familial and environmental influences.[7,8] The images that young people see in the media are also likely to influence their perceptions of what is an acceptable body shape and size [7]. Anorexia has a prevalence of 0.3% in young women and has the highest mortality of any psychiatric disorder, it is the leading cause of admission to child and adolescent psychiatric services. 80–90% of those affected are female and the average age of onset is 15 years [8,9].

It has been hypothesised that the continual emphasis placed on CF patients regarding their dietary intake and weight could place them at increased risk of developing abnormal eating patterns. Although studies have reported an increased incidence of behavioural eating problems in CF patients, when strict diagnostic criteria are used there has been no increase in the incidence of anorexia or bulaemia [10–13]. One study has actually reported fewer problems with perceived weight and body image in CF females when compared to their healthy peers [14]. Although the relationship between CF and eating disorders remains unclear, the medical and general health consequences of weight loss in CF patients is likely to be greater when compared with similar weight loss in healthy patients.

In patients with CF management of inadequate weight gain related to abnormal body image or anorexia is complex. It must involve close interaction between the patient, family, physician, dietician and psychologist. Strategies to improve weight gain include the use of oral supplements and enteral feeding but unless the underlying psychological issues are addressed they are unlikely to be successful in the long term [2,12].

It is accepted that patients with CF can have successful pregnancies without affecting their long-term prognosis [3]. Factors that predict a good outcome for mother and baby include: good nutritional status and less severe pulmonary dysfunction at conception, maintenance of lung function during pregnancy and a weight gain of >10 kg during the pregnancy. [4,5]. Given this patient's nutritional status, lung function at conception and issues with weight gain there was a very high risk that there would be major complications for her or her baby should the pregnancy progress.

Patients with CF who are planning a pregnancy must have regular discussions with the CF and obstetric staff about the effect CF has on the pregnancy and the effect the pregnancy has on their CF control. Prior to and during the pregnancy the patient's general health and nutritional status must be optimised to reduce possible side effects. Unplanned pregnancies require a frank and open discussion about the prognosis for mother and baby so that the patient can make an informed decision as to whether she should continue with the pregnancy. Psychology input is vital as such decisions will inevitably have long-term consequences.

We report this patient to highlight the difficulties that arise when a patient with CF has an eating disorder. It is important

that we look for evidence of eating disorders in patients with CF who are not gaining weight, so that they can be identified early and the appropriate psychological, medical and nutritional support can be given. This history also highlights the complex issues that arise when a patient with CF becomes pregnant, especially when her nutritional status is poor in the presence of a recognised eating disorder.

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