

# Treatment compliance in adults with cystic fibrosis

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## Abstract

**Background** – The study comprised three interrelated aims: (1) to ascertain (a) patient compliance with physiotherapy, exercise, enzyme and vitamin regimens, (b) how compliance was perceived by patients, and (c) the reasons for poor compliance; (2) to identify demographic and clinical variables associated with compliance; and (3) to determine how accurately patient compliance can be predicted by carers.

**Methods** – Demographic and medical history data were obtained from medical records and a patient questionnaire. The data obtained included age, sex, employment status, inpatient or outpatient status, frequency of contact with the clinic, age at diagnosis, and the number of years practising physiotherapy. Measures of clinical status, including FEV<sub>1</sub> and FVC percentage predicted, Shwachman score, and 24 hour sputum weight were recorded before completion of the questionnaire. The questionnaire, administered by a psychologist, assessed the reported degree of patient compliance, their perception of compliance, and their reasons for poor compliance.

**Results** – Sixty patients participated in the study and 51/60 and 41/55 patients were considered compliant with enzyme and exercise therapies, respectively. Compliance was lower with physiotherapy (32/60) and vitamin treatment (21/45). Patients reporting immediate benefits following exercise and physiotherapy were more compliant than those reporting no improvement. The perception by patients that compliance was sufficient (“about right”) was physiotherapy 67%, exercise 37%, enzymes 78%, and vitamins 9%. Compliance was not influenced by demographic details nor by severity of disease, although patients producing large amounts of sputum and receiving help with physiotherapy were more compliant with physiotherapy. The physiotherapist and physician judged correctly the degree of compliance with physiotherapy in 83% and 75% of cases, respectively, and with exercise in 68% and 67% of cases, respectively.

**Conclusions** – The reported degree of compliance and reasons for poor compliance were treatment specific. Demographic and disease severity variables were not associated with compliance. Those involved in the care of patients

with cystic fibrosis were able to predict patient compliance.

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An increasing number of patients with cystic fibrosis are surviving into adulthood; this has been attributed to earlier diagnosis, specialist care, and more effective methods of treatment.<sup>1-4</sup> Compliance, defined as the degree of patient adherence to medical advice and treatment regimens, may be an important factor in the successful management of the disease.

The daily management includes physiotherapy, exercise, oral and inhaled medication for the respiratory system, and oral pancreatic enzymes and vitamin supplements for the control of malabsorption. Those patients awaiting heart-lung transplantation may additionally need to manage home gastrostomy feeding and nocturnal ventilation. A complex and time consuming regimen of self care is therefore expected of the patient.

There is no conclusive link between poor compliance with treatment and progressive disease in cystic fibrosis. However, non-compliance with treatment and medical advice may cause accelerated disease, wasted resources, increased outpatient visits, and more admissions to hospital, and the ability to predict the effectiveness of treatment may be impaired.

Previous studies of compliance have concentrated on children using parental reporting, or have been confounded by combining the results of children and adults.<sup>5-7</sup> Little attention has been given to adults who are often striving for independence with their management regimens. In addition, these studies have suffered from poor experimental design, with data obtained whilst in hospital or from medical records, and use of insensitive scoring systems. Most have assessed several treatment regimens but have combined the data to provide an overall score, thereby losing specific treatment data.<sup>7-9</sup> An overall compliance score fails to recognise that patients may comply, to varying degrees, with different components of a treatment regimen. In a study of adult patients with cystic fibrosis 76% took their prescribed drugs 90% of the time, while only 54% of patients adhered to their physiotherapy regimens and 57% to their exercise regimens.<sup>10</sup>

In order to improve compliance, factors which predict compliance need to be identified, together with the reasons for poor adherence. This study aimed to investigate these areas in adults with cystic fibrosis.

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## Methods

### SUBJECTS

Consecutive patients attending the Monsall Adult Cystic Fibrosis Unit were invited to take part in the study. It was intended to recruit half the patients attending the unit, and 67 patients were approached.

### INTERVIEW

Each patient was interviewed during a period of clinical stability by a psychologist and guided through the compliance questionnaire (see appendix on page 120). The accuracy of the interview was validated by asking a close companion (usually mother or partner) questions phrased in a similar manner about the patient's degree of compliance. To minimise the "faking of good effect" by patients, interviews were conducted away from the wards or treatment areas by those not directly involved in patient treatment. The importance of confidentiality was emphasised.

### QUESTIONNAIRE

There are no published measures of compliance with treatment appropriate for cystic fibrosis. A questionnaire was designed by the authors that measured three aspects of compliance for each of the four treatment components: physiotherapy, exercise, pancreatic enzymes, and vitamins. The three aspects of compliance were (1) the degree of adherence to medical advice or treatment; (2) patient perception of whether treatment was sufficient; and (3) the reasons for non-compliance.

#### *Measures of degree of compliance with treatment*

(a) Physiotherapy: adherence with physiotherapy was measured on a six point scale (question 5, appendix).

(b) Exercise: patients were asked three questions about their level and frequency of exercise (questions 8, 9, and 10, appendix). The degree of benefit was assessed by the physiotherapist according to the exercise capacity based on exercise testing and disease severity.

(c) Enzymes: questions related to enzymes taken with main meals and those taken with snacks were scored on a four point scale (questions 13 and 16, appendix).

(d) Vitamins: adherence with vitamins was marked on a four point scale (question 22, appendix).

The questionnaire also included general questions for some treatments – for example – “do you have help with your physiotherapy,” “do you feel better following physiotherapy and exercise,” “are you prescribed vitamins?” The timing of pancreatic enzyme administration during meals was also ascertained (appendix).

#### *Measures of patient perception of compliance*

For each treatment modality patients were asked to choose from one of four statements:

“about right,” “not enough,” “too much,” and “don't know” (questions 7, 12, 18, and 24, appendix).

#### *Measures of patient reasons for poor compliance*

Patients selected their reasons for poor compliance from a list for each of the four treatments (appendix). They were also encouraged to add other reasons of their choice.

#### *Self prescribed medication*

Details of frequency and type of self prescribed medication were collected (questions 25–27, appendix).

### DEMOGRAPHIC DATA

#### *Medical history*

Details of age, sex, employment status, and age at diagnosis were obtained from medical records. The number of clinic visits in the previous year and contact with carers for inpatient and outpatient treatment was compared. The number of years of practising physiotherapy and any help received with physiotherapy were validated by patients' responses to the questionnaire.

#### *Clinical measures*

At the time the questionnaire was administered each patient was seen by two physicians to obtain a Shwachman score. Measurements were made of respiratory function (FEV<sub>1</sub> % predicted and FVC % predicted) and 24 hour sputum weight (> 35 g/day = large volume sputum producer, < 35 g/day = small volume sputum producer).

### PREDICTORS OF COMPLIANCE

A predicted degree of compliance with physiotherapy and exercise was made independently by the physiotherapist and physician on a similar scale to that completed by the patient.

### STATISTICAL ANALYSES

Data analyses were performed with the Statistical Package for the Social Sciences (SPSS). Associations between the degree of compliance and demographic and clinical variables were analysed by the  $\chi^2$  test. Comparisons between patients and close companions were tested by the Mann-Whitney U test.

## Results

Of the 67 patients, 25 women and 35 men completed the questionnaire and seven declined to take part. There were no demographic or medical differences between the participating and non-participating patients. The mean age and FEV<sub>1</sub> % predicted of the patients in the study were 20.98 years (range 16–44) and 59.4% (range 10–103%) respectively. All study population means and percentages were

**Table 1** Reported degrees of compliance with physiotherapy, exercise, enzyme, and vitamin regimens by patients and close companions

Degree of compliance	Patients	Close companions
<b>Physiotherapy (n = 60):</b>		
Once or twice per day	19 (32)	21 (35)
Occasionally miss	13 (21)	13 (21)
Often miss one or two days	4 (7)	5 (8)
Often miss many days	6 (10)	5 (8)
Only when ill	10 (17)	7 (12)
Never	8 (13)	9 (15)
<b>Exercise (n = 55):</b>		
Exercising beneficially	41 (75)	38 (69)
Not exercising	14 (25)	17 (31)
<b>Enzymes (n = 60):</b>		
Always	51 (85)	56 (93)
Usually	7 (12)	4 (7)
Occasionally	2 (3)	0 (0)
Never	0 (0)	0 (0)
<b>Vitamins (n = 45):</b>		
Always	21 (47)	25 (56)
Usually	16 (36)	18 (40)
Occasionally	7 (15)	2 (4)
Never	1 (2)	0 (0)

Values in parentheses are percentages.

representative of the total population attending the Monsall Adult Cystic Fibrosis Unit.

**INTERVIEW**

No significant differences emerged between the responses of patients and their close companions for the four treatment regimens.

**MEASURES OF COMPLIANCE**

*Degree of compliance* (table 1)

(a) **Physiotherapy:** the six compliance categories were condensed into three groups, giving 32 patients who were considered compliant, 10 partially compliant, and 18 patients who were non-compliant.

(b) **Exercise:** five of the 60 patients did not perform exercise because of the severity of their disease. Of the remainder 41 were considered to be exercising beneficially by the physiotherapist, with 14 failing to reach a beneficial level. From the general questions 28 and 35 patients reported that their chest felt better following physiotherapy and exercise, respectively. They also complied with exercise to a greater degree than patients reporting no improvement ( $p < 0.01$ ).

(c) **Enzymes:** most patients (n=51) always took enzymes with main meals, seven usually did, and two occasionally complied with the treatment regimen. The taking of enzymes with snacks revealed a poor degree of compliance: 13 patients always took enzymes with snacks, 27 usually did, 14 occasionally did, and six never did. Over half the patients (53%) consumed the enzymes throughout the meal, while the remainder of the sample took them at the start or the end of the meal.

**Table 2** Patients' perception of their compliance with physiotherapy, exercise, enzyme and vitamin regimens

	About right	Not enough	Too much	Don't know
Physiotherapy (n = 60)	40 (67)	15 (25)	0 (0)	5 (8)
Exercise (n = 55)	20 (37)	32 (58)	0 (0)	3 (5)
Enzymes (n = 60)	47 (78)	5 (8)	2 (4)	6 (10)
Vitamins (n = 45)	4 (9)	19 (42)	1 (2)	21 (47)

Values in parentheses are percentages.

(d) **Vitamins:** only 45 of the patients were prescribed vitamins. Of these, 21 always took their vitamins, 16 usually did, seven occasionally did, and one never did.

Overall, for all four treatments 18 patients were fully compliant, eight failed to do anything regularly, and the remaining 34 complied, to varying degrees, with the treatments.

Twenty patients reported that they never took non-prescribable medication, 33 did occasionally, and seven usually self-prescribed. These medications included vitamins and "over the counter" cough remedies.

*Patients' perception of compliance* (table 2)

(a) **Physiotherapy:** most patients (n = 40) considered their daily amount of physiotherapy to be about right, but 15 believed that they did insufficient physiotherapy. There were no patients who thought they did too much physiotherapy and five were unsure.

(b) **Exercise:** only 20 patients believed they were exercising sufficiently, 32 considered they were doing too little, none reported doing too much exercise, and three didn't know.

(c) **Enzymes:** most patients (n = 47) believed their enzyme intake was sufficient. Of the remaining 13 patients, five reported insufficient intake while excess intake was recorded by two, and six didn't know.

(d) **Vitamins:** only four patients thought their intake was correct; 19 thought they did not take enough vitamins, one patient considered the intake to be too much, while 21 patients did not know whether their intake was correct.

*Reasons given by patients for poor compliance* (table 3)

Three common reasons could be recorded for non-compliance with each treatment. Twenty seven patients believed they were well without treatment; more than one third considered their disease to be less serious than others with cystic fibrosis, and 12 believed exercise could replace physiotherapy. Embarrassment and interference with social life were additional

**Table 3** Reasons for poor compliance with physiotherapy, exercise, enzyme, and vitamin regimens

Predominant reasons for poor compliance	n
<b>Physiotherapy (n = 60):</b>	
Well without physiotherapy	27 (45)
Not enough time	24 (40)
Can't be bothered	24 (40)
Less serious than others	22 (37)
Interrupts social life	21 (35)
Simply forget	13 (22)
Exercise instead	12 (20)
It's embarrassing	9 (15)
<b>Exercise (n = 55):</b>	
Not enough time	21 (38)
Can't be bothered	19 (35)
Simply forget	16 (29)
<b>Enzymes (n = 60):</b>	
Simply forget	27 (45)
It's embarrassing	16 (27)
Can't be bothered	7 (12)
Interrupts social life	7 (12)
<b>Vitamins (n = 45):</b>	
Simply forget	26 (58)
Can't be bothered	13 (29)

Values in parentheses are percentages.

reasons for poor compliance with pancreatic enzyme therapy.

#### COMPLIANCE: DEMOGRAPHIC AND CLINICAL VARIABLES

Patients complied better with physiotherapy if they received help with it ( $p=0.02$ ) or produced large amounts of sputum ( $p=0.02$ ). The remaining clinical and demographic variables were not associated with levels of compliance.\*

#### PREDICTIONS OF COMPLIANCE BY PHYSIOTHERAPIST AND PHYSICIAN

The physiotherapist and physician involved in the daily care of the patients correctly judged the degree of compliance with physiotherapy for 69% and 66% of patients, respectively. Condensing the six compliance categories into three gave correct predictions of 83% and 75% for physiotherapist and physician, respectively. Compliance with exercise was accurately predicted by the physiotherapist in 68% of patients, and by the physician in 67%.

#### Discussion

Previous studies have consistently shown overall compliance rates with treatment of 50%.<sup>11-14</sup> In our study compliance with treatment and advice differed for each of the four treatment types: physiotherapy, exercise, pancreatic enzymes, and vitamin supplements. Compliance with physiotherapy and vitamin taking was less than the reported adherence to pancreatic enzyme taking and exercise in our patients. Our study suggests that patients may use their immediate symptoms as "barometers" to decide when to discontinue or continue treatment. Patients therefore focus on the short term rather than the long term benefits of treatment. This is emphasised by the fact that the lowest adherence rates occurred when there was no immediate risk or discomfort associated with poor compliance. Conversely, compliance improves when the treatment provides immediate benefits that patients can recognise. Compliance with enzyme regimens is high in order to avoid steatorrhoea, but low with vitamin therapy which has no apparent benefit. Only half of our patients reported that their chest felt better immediately after physiotherapy compared with 70% who perceived an immediate improvement following exercise. Patients reporting immediate benefits complied more than those experiencing no immediate improvement. This supports the suggestion that patients who believed that their treatment was beneficial were more likely to comply.<sup>8</sup>

The degree of compliance may be influenced by patient perception and understanding of the requirements of self treatment. This was evident in this study where 75% of patients exercised to a beneficial level, but only 37% considered this was sufficient. This is in

accordance with currently held views that exercise is compatible with a healthy lifestyle. In contrast, only half the patients were considered compliant with physiotherapy, yet 67% believed that they did enough. The major reasons for poor adherence with physiotherapy were that patients believed they were well or that the severity of their disease was less than that of others. Exercise was considered an alternative to physiotherapy in 20% of patients. These results confirm the finding that physiotherapy is the least tolerated aspect of treatment, as reported by both children and their parents,<sup>15</sup> with adherence rates between 40% and 54% whether performed by parent or patient.<sup>6,10</sup> Exercise may have been better complied with because, unlike physiotherapy, it is probably more acceptable to adults with cystic fibrosis and can be shared with their peers.

The demographic details of the patients had no influence on compliance apart from physiotherapy, where greater adherence was seen in those who received help or produced large volumes of sputum. Similarly, in paediatric clinics in North America parental compliance with antibiotic treatment was not associated with demographic and severity variables.<sup>5,7,8</sup> In contrast, based on parental (for young children) and patient reporting, greater adherence to antibiotic and vitamin regimens correlated with lower Shwachman scores.<sup>6</sup>

Physicians have previously been reported to be poor at recognising patients who are compliant or non-compliant with the taking of medication,<sup>16,17</sup> although a director of a paediatric cystic fibrosis clinic correctly identified requirements for antibiotic treatment in 80% of cases.<sup>5</sup> In this study both the physician and the physiotherapist differentiated between compliant and non-compliant patients for exercise and physiotherapy in most cases. Accurate predictions of compliance made by those involved in care of the patients probably results from a high level of continuing medical care and lifelong informal contact with the patient and family. This ability to predict compliance did not influence the level of adherence by patients, but it may assist the carers in assessing efficacy of treatment.

It may be unrealistic to expect young adults with cystic fibrosis to follow absolutely treatment advice as they attempt to strike a balance between their needs and the daily time consuming treatment regimens. This study found no associations between demographic or clinical variables and compliance with treatment. Severity of disease and the long term benefits of treatment regimens may not ensure compliance if the patient does not share the perceptions of the carers.

Compliance may be improved by offering patients the choice of treatments they prefer. We have previously shown that, when patients are given a choice between physiotherapy alone, exercise alone or the two combined, two thirds preferred the latter option.<sup>18</sup>

A crucial time when compliance needs to be enhanced is when patients are transferring from paediatric to adult care. Although patient independence and self involvement are

\* Data available from authors on request.

encouraged, the interest and support from family and partners are crucial.

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Appendix

The Manchester Cystic Fibrosis Compliance Questionnaire

The following questions ask you about your treatment. So that we can assess how effective your treatment is, please answer all the questions honestly.

- 1 How often do you attend the CF outpatient clinic? How often do you attend as an inpatient?

Physiotherapy

- 2 What age were you when you started having physiotherapy? What made you start?

- 3 Do you have help with your physiotherapy? If YES, please give details

- 4 How many times each day, has it been agreed, that you should do your physiotherapy?

- 5 Over the last three months, which of the following statements best describe you?

- I do my physiotherapy once or twice each day, every day. Occasionally I miss one or two days physiotherapy. I often miss one or two days physiotherapy. I often miss several days physiotherapy. The only time I do my physiotherapy is when I feel unwell. I never do my physiotherapy.

- 6 Please tick the boxes which best describe you. When I miss my physiotherapy it is usually because:

- I feel well without treatment. It interferes with my social life. There isn't enough time. I have to rely on someone to help me. I simply forget. My CF isn't as serious as most of the other CF patients. It interferes with family routine commitments. I can't always be bothered. I don't believe that it does me any good. I have too many different treatments to attend to, and physiotherapy is the least important of them. It makes me feel worse. I don't fully understand why I need to do physiotherapy. I do plenty of exercise, so I don't need to do physiotherapy. I don't know how to do it. I have difficulty doing my own physiotherapy. I resent having to do it. It's embarrassing.

- 7 Do you think that the amount of physiotherapy you do is:

Tick one box only About right Not enough Too much Don't know

Exercise

- 8 Do you do any exercise?

- 9 If YES, what do you do and how often?

- 10 If YES, why do you exercise?

- 11 If I don't exercise at all, or my usual exercise sessions lapse, it tends to be because:

- Tick as many boxes as you like I don't enjoy exercise. I simply forget. Most of the time I don't feel well enough to exercise. I resent having to exercise. I don't fully understand why I should exercise. I have too many different treatments to attend to, and exercise is the least important of them. I don't believe that it does me any good. I haven't enough time. I don't want to lose weight. I can't always be bothered. Exercise makes me feel worse. It interferes with my social life. Exercise makes me too breathless.

- 12 Do you think your present level of exercise is:

Tick one box only About right Not enough Too much Don't know

Pancreatic enzymes

- 13 Do you take your enzymes with a MAIN meal?

Tick one box only Never Occasionally Usually Always

- 14 How many do you usually take with a MAIN meal?

- 15 With a MAIN meal do you take them:

- Tick one box only Throughout the meal. Only at the beginning of the meal. Only at the end of the meal.

- 16 Do you take them with snacks?

Tick one box only Never Occasionally Usually Always

- 17 If I don't take my enzymes it is usually because:

- Tick as many boxes as you like I only take them when they are given to me. I am embarrassed to take them in front of other people. I don't like the taste. I have difficulty swallowing them. I have difficulty getting repeat prescriptions. I simply forget. My body occasionally needs a rest from medication, otherwise I may become immune to them, and they will not work when I really need them. I only take enzymes when I feel unwell. I resent having to take them. I don't want my friends colleagues to know that I have CF. I don't fully understand why I need to take them. My CF isn't as serious as most of the other CF patients. I have too many different treatments to attend to, and this is the least important of them. I don't believe that they do me any good. I can't always be bothered. They make me feel worse. It interferes with my social life.

- 18 Do you think that your pancreatic enzyme intake is:

Tick one box only About right Not enough Too much Don't know

- 19 Do you eat whatever you like?

Yes No

- Do you eat a fat-free diet?

Yes No

- Do you eat a vegetarian diet?

Yes No

Vitamins

- 20 Are you prescribed vitamins?

Yes No

- 21 If YES, what has been prescribed, and how often should you take them?

- 22 How often do you actually take your vitamins?

Tick one box only Never Occasionally Usually Always as prescribed

- 23 If I don't take my vitamins as prescribed it is usually because:

- Tick as many boxes as you like I only take them when they are given to me. I don't like the taste. I have difficulty swallowing them. I take more than has been prescribed for me. I have difficulty getting repeat prescriptions. They make me feel worse. I simply forget. My body occasionally needs a rest from medication, otherwise I may become immune to them, and they will not work when I really need them. I only take vitamins when I feel unwell. I resent having to take them. I don't want my friends colleagues to know that I have CF. I don't fully understand why I need to take them. My CF isn't as serious as most of the other CF patients. I have too many different treatments to attend to, and this is the least important of them. I don't believe that they do me any good. I can't always be bothered.

- 24 Do you think that your vitamin intake is:

Tick one box only About right Not enough Too much Don't know

- 25 Do you take any medication which has not been prescribed by a doctor?

Never Occasionally Usually Always

- 26 What do you take, and how often?

- 27 Why do you take it?