Cystic Fibrosis Patients’ Views and Beliefs About Chest Clearance and Exercise – A pilot study

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Key Words
Cystic fibrosis, adherence, physiotherapy, opinions.

Summary
Understanding the health beliefs related to reasons for adherence and non-adherence to a physiotherapy programme is important in planning an effective chest clearance programme for a person with cystic fibrosis. A pilot questionnaire was undertaken with 96 adults with cystic fibrosis randomly selected from patients on a hospital register. Response rate was 54%. It was not possible to obtain information from non-responders. Patients reported the treatment techniques they used. A combination of deep breaths, gentle breathing and huffing (active cycle of breathing techniques) were the most commonly used techniques to clear secretions (42/50). Almost half of the patients said that they would not prefer help with their chest physiotherapy at home, indicating that they would rather undertake it themselves. More than three-quarters of the patients who answered this question felt physiotherapy was either ‘very helpful’ or ‘helpful’ when unwell. More than three-quarters of the patients agreed or strongly agreed that doing physiotherapy was important to their feelings of well being (42/50) and stopped their chest deteriorating (45/50).

The three most common themes for not doing chest physiotherapy identified from the open questions were ‘feel very well’, ‘too tired’ and ‘not enough time’. The most important themes identified as to why patients did chest physiotherapy included ‘makes my chest clearer’, ‘feel better afterwards’, ‘lessens my risk of infection’ and ‘stops me from coughing’.

Introduction
Increasingly the term ‘patient compliance’ is being replaced by the terms ‘patient co-operation’ or ‘patient adherence’, as these terms suggest that therapists or doctors seek negotiation with and active participation of patients in their treatment programme (Petchey and Murphy, 1992; Ramsden, 1988).

Patient adherence to medical advice is a multifactorial issue; the factors which affect adherence differ depending on the chronicity of disease (Meyers et al, 1975). With regard to adherence to treatment in patients with cystic fibrosis, previous studies have reported that age, sex, severity of disease – as measured by Shwachman score (Shwachman and Kulczycki, 1958) – and age at diagnosis had no effect on adherence to treatment (Meyers et al, 1975; Fong et al, 1990; Passero et al, 1981). However, there was a relationship between adherence to prescribed treatment and perception of disease severity (Fong et al, 1990; Meyers et al, 1975; Abbott et al, 1994), the nature of the doctor patient relationship (Meyers et al, 1975), the immediate perceived benefit of treatment (Abbott et al, 1994) and how the treatment was individualised (Muszynski-Kwan et al, 1988).

Other factors which have been relevant in treatment adherence with other chronic conditions, but which at present remain under-explored in cystic fibrosis, are the patients’ degree of knowledge and understanding, the complexity of the treatment regimen (Charney, 1972) and the length of treatment time (Currie et al, 1986).

Patients’ co-operation with and adherence to treatment may also be influenced by their own internal system of health beliefs. In health care, patients do not necessarily accept what they are told; any information or required action needs to make sense and be justifiable to them. They all weigh up the potential value of treatment against the potential inconvenience/side effects and make a decision about their participation accordingly. The nearer the professionals’ advice is to the individuals’ lay beliefs the more willing they are to accept it (Donovan et al, 1989).

Individual beliefs help determine how people see the world. They are altered by a variety of factors: interpersonal influences, life events, health care intervention, perceived severity of illness, and psychological barriers (Rosenstock, 1974).

In order to understand adherence and non-adherence to physiotherapy it is important to elicit and understand each patient’s beliefs. To improve patient adherence to treatment it is essential to be sensitive to the patients’ preferences when structuring and modifying treatment (Braker et al, 1984).

The aims of this pilot study were to investigate:

- What ‘physiotherapy and exercise’ is done by patients with cystic fibrosis.
- Patients’ attitudes and beliefs about chest clearance and exercise.
- Patients’ reasons for adherence and non-adherence to chest clearance treatment.
Questionnaire

1. How long have you been attending Royal Brompton Hospital? Please tick one box only
   (a) Less than 6 months   (b) More than 6 months but not more than 2 years   (c) More than 2 years
2. Are you also under the care of a doctor at another hospital? Yes No
3. Are you Female Yes No
4. How old are you (in years) ............................................
5. Are you working full time? Yes No
   Are you working part time? Yes No
6. Are you caring for others eg children/dependents? Yes No
7. When was it known that you had cystic fibrosis? (approx age) ............................................
8. Did you start physiotherapy at the time of diagnosis? Yes No Don’t know
9. Over the last 6 months how unwell do you feel you have been? Please tick one box only
   Very well    Well    Unwell    Very unwell
10. How much do you agree or disagree with the following statement? ‘Doing physiotherapy is important to my feeling of well being’ Please tick one box only
    Strongly agree    Agree    Neither agree nor disagree    Disagree    Strongly disagree
11. How much do you agree or disagree with the following statement? ‘Doing physiotherapy will prevent my chest deteriorating’ Please tick one box only
    Strongly agree    Agree    Neither agree nor disagree    Disagree    Strongly disagree
12. What benefits do you think you should obtain from regular physiotherapy at home? ............................................
13. About how much sputum have you produced in the last 24 hours? Please tick one box only
    (a) Less than a tablespoon   (b) More than a tablespoon, but less than a teacupful   (c) About a teacupful   (d) More than a teacupful
14. At home do you use any of the following? Please tick relevant boxes.
    PEP mask    Flutter    Mechanical percussor    Air compressor and nebuliser    Autogenic drainage    Postural drainage frame or tipping board    Self chest clapping    Huffing    Breathing control    Deep breathing
15. How often do you do physiotherapy at home? ............................................
16. What makes you think it is time to stop a physiotherapy session? ............................................
17. How long did your last physiotherapy session take, excluding the time you use your nebuliser? ............................................
18. What do you feel helps most in clearing your secretions? ............................................
19. How helpful do you think physiotherapy is when you are well? Please tick one box only
    Very helpful    Helpful    Not helpful    Unhelpful
20. How helpful do you think physiotherapy is when you are unwell? Please tick one box only
    Very helpful    Helpful    Not helpful    Unhelpful
21. At home do you feel able to follow advice given by the physiotherapists at Royal Brompton Hospital? Please indicate your view by ticking one box below
    Most of the time    Some of the time    Not often    Never
22. At home would you prefer to have someone to help you with physiotherapy? Please tick one box.
    (a) Most of the time   (b) Only when unwell   (c) Never
23. Does someone help you with your physiotherapy at home? Please tick one box.
    Yes    No    Not applicable
24. What benefits do you feel you gain from having someone help with your treatment? ............................................
25. Have you altered your physiotherapy in the last 6 months? Please tick relevant box
    Yes    No
26. If you answered yes to question 25, please give the reasons that made you alter it ............................................
27. You may or you may not do regular physiotherapy at home. If you do not do regular physiotherapy, please go to question 28. If you do regular physiotherapy, why do you do it? (Please answer this and also question 28) ............................................
28. Are there reasons for you not doing physiotherapy? ............................................
29. Please indicate your thoughts on exercise by ticking one box only. I think I would benefit from regular exercise
    Uncertain    I don’t think I would benefit from regular exercise
30. Do you take any form of exercise for example cycling, swimming, walking, sport at school or college etc? Please list:
31. During the last six months on average how many times a week did you spend exercising? ............................................
32. During the last six months on average how many times a week did you exercise? ............................................
33. Do you think exercise can be substituted for physiotherapy? Yes No Don’t know
34. If you attend the physiotherapy out-patient department at the time of your doctor’s appointment what do you think is the main purpose of this visit? ............................................
35. Do you feel you are given consistent advice about physiotherapy? Please indicate your view by ticking one box
    Always consistent    Usually consistent    Sometimes consistent    Inconsistent
36. Are there any other comments you would like to make about your physiotherapy? ............................................
In the context of this paper the term 'physiotherapy' is used to mean sputum clearance. In discussion with patients with cystic fibrosis attending Royal Brompton Hospital (RBH) and in a previous pilot it was the term patients used to describe their sputum clearance (either self-treatment or with help), anything else they might do (eg exercise, postural maintenance awareness programmes) was not defined by them as 'physiotherapy'.

Methods

Subjects
From a total of 600 patients (16 years and over) attending the adult cystic fibrosis unit at RBH, 100 were selected for the study by computer-generated random numbers.

Questionnaire
A postal questionnaire with anonymous forms were sent with a stamped addressed envelope, for return within two weeks to a secretary at RBH. The questionnaire consisted of 22 closed questions (six in the form of Likert scales) and 14 open questions (fig 1).

In addition to this, patient characteristic data and recent (ie within the last six months) lung function results were obtained from the patients’ medical notes.

Data Analysis
The closed questions were analysed using simple counts and percentages. The open questions were content analysed by the researcher and two independent observers (Burnard, 1991; Nachmias and Nachmias, 1992). Spearman’s rho correlation coefficient was calculated to determine relationships between the answers for the open and closed questions. Spearman’s rho was chosen because the data was non-parametric. An unpaired t-test was used to test relationships between lung function and the closed questions, as lung function is a continuous variable.

Results
Of the 100 questionnaires sent out, four were returned 'not known at this address'. Of the 96 patients who received questionnaires, 52 (54%) returned them. The data from one patient who had undergone heart lung transplant and from another who answered only six questions (patient characteristic information only) were excluded. Patient characteristic data are presented in table 1. Lung function data were available for 22 of the patients.

Self-reported Physiotherapy and Exercise Profile
From the closed questions it was found that the median amount of sputum produced by a physiotherapy session was more than a tablespoon but less than a teacupful, and the majority of the patients spent between 10 and 30 minutes on a physiotherapy session (table 2). The treatment techniques and adjuncts used in sputum clearance are shown in figure 2. For the group as a

Table 1: Patient characteristics (n = 50)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. (%)</th>
</tr>
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<tbody>
<tr>
<td>Work full time</td>
<td>21 (42%)</td>
</tr>
<tr>
<td>Work part time</td>
<td>7 (14%)</td>
</tr>
<tr>
<td>Not in work</td>
<td>22</td>
</tr>
<tr>
<td>Attended Royal Brompton Hospital</td>
<td>&gt;2 years (96%)</td>
</tr>
<tr>
<td>Shared care with another hospital</td>
<td>16 (32%)</td>
</tr>
<tr>
<td>Started physiotherapy at time of diagnosis</td>
<td>35 (70%)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>21</td>
</tr>
<tr>
<td>Female</td>
<td>29</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>% predicted FEV₁</th>
<th>% predicted FVC</th>
</tr>
</thead>
<tbody>
<tr>
<td>26.1</td>
<td>47</td>
<td>66.5</td>
</tr>
<tr>
<td>6.7</td>
<td>24</td>
<td>23.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age at diagnosis</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–6 months</td>
<td>48%</td>
</tr>
<tr>
<td>7 months–9 years</td>
<td>40%</td>
</tr>
<tr>
<td>10–20 years</td>
<td>12%</td>
</tr>
</tbody>
</table>

Table 2: Length of time spent on a physiotherapy session (n = 46)

<table>
<thead>
<tr>
<th>Duration (minutes)</th>
<th>No of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 10</td>
<td>5</td>
</tr>
<tr>
<td>10 to 20</td>
<td>19</td>
</tr>
<tr>
<td>21 to 30</td>
<td>12</td>
</tr>
<tr>
<td>31 to 40</td>
<td>3</td>
</tr>
<tr>
<td>41 to 50</td>
<td>1</td>
</tr>
<tr>
<td>51 to 60</td>
<td>5</td>
</tr>
<tr>
<td>More than 60</td>
<td>1</td>
</tr>
</tbody>
</table>

Fig 2: Techniques and adjuncts used in sputum clearance
whole the patients' preferences for help with home physiotherapy are shown in figure 3. In a separate question 42% of patients said they had help with physiotherapy at home. 75% said they took exercise, and the amount taken each week can be seen in table 3. The most commonly reported types of exercise were 'walking' (21/35), 'cycling' (10/35), 'swimming' (9/35), 'dancing' (5/35), and 'weights' (5/35).

Table 3: Amount of exercise taken per week (n = 49)

<table>
<thead>
<tr>
<th>Duration (hours)</th>
<th>No of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than half</td>
<td>9</td>
</tr>
<tr>
<td>Half to 1</td>
<td>6</td>
</tr>
<tr>
<td>More than 1, less than 2</td>
<td>5</td>
</tr>
<tr>
<td>More than 2, less than 3</td>
<td>3</td>
</tr>
<tr>
<td>More than 3, less than 4</td>
<td>3</td>
</tr>
<tr>
<td>More than 4, less than 5</td>
<td>4</td>
</tr>
<tr>
<td>More than 5, less than 6</td>
<td>2</td>
</tr>
<tr>
<td>More than 6</td>
<td>6</td>
</tr>
<tr>
<td>Other comments unquantifiable</td>
<td>11</td>
</tr>
</tbody>
</table>

Patients' Reasons for Adherence/Non-adherence

The most important themes identified for adherence to a physiotherapy programme were: 'makes my chest clearer' (21/38), 'feel better afterwards' (10/38), 'so I can do more' (8/38), 'lessens my risk of infection' (8/38), 'makes my breathing easier' (8/38), 'without it I'd become ill' (7/38), and 'stops me from coughing' (7/38).

With regard to non-adherence the most common reasons given for not doing physiotherapy were 'not enough time' (9/38), 'too tired' (6/38), 'don't need to when well' (5/38), and 'makes the most of the time for something else' (4/38).
Statistical Tests

Spearman's correlations between variables (n = 50)

There was a statistically significant correlation between the following:

The belief that doing physiotherapy was important to their feeling of well being and how helpful they reported physiotherapy was when well: \( \rho = 0.64 \) (p = 0.00).

The belief that doing physiotherapy was important to their feeling of well being and how helpful they reported physiotherapy was, when unwell: \( \rho = 0.42 \) (p = 0.003).

The belief that doing physiotherapy was important to their feeling of well being and length of reported time spent on physiotherapy: \( \rho = -0.466 \) (p = 0.001).

Unpaired t-tests (n = 22)

There was a statistically significant difference in FEV\(_1\) between:

Patients who reported feeling they had been very well or well in the last six months and those feeling unwell or very unwell: \( t = 2.26 \) (p = 0.04).

Patients who reported physiotherapy as being very helpful or helpful when well and those reporting it as being not helpful or unhelpful: \( t = -3.34 \) (p = 0.021).

Patients who strongly agreed or agreed with the statement 'Physiotherapy is important to my feeling of well being' and those who disagreed or disagreed strongly: \( t = -4.3 \) (p = 0.013).

For the other closed questions t-tests could not be attempted because patients' answers were almost unanimous in terms of their agreement with the statement.

Discussion

The majority of respondents held positive beliefs about physiotherapy and exercise and the benefits they obtain from them. However, it was not possible to obtain information from non-responders and this may have biased the results.

Previous studies have shown some patients fail to comply even when they are regularly reminded to do so and understand why it is necessary (Facchinetti, 1987). There must therefore be other reasons for adherence to a physiotherapy programme. Each patient's beliefs must be taken into consideration when negotiating a proposed treatment programme.

In this study the length of treatment time was significantly correlated with a strong belief that physiotherapy improved patients' feeling of well being and control over their condition; those who felt this most strongly did more physiotherapy. Patients reported perceived physical benefits from physiotherapy as some of the major reasons for doing it, and along with this held a strong belief that doing physiotherapy prevented them from becoming ill. This is in agreement with Czajkowski and Koocher (1987). It would be interesting to explore further whether those patients with strong positive health beliefs about physiotherapy had a strong internal locus of control in their overall health. It may be that quite different approaches are necessary for those patients who believe they have the greater personal control over their health, and for those who see powerful others such as the doctor/physiotherapist as most important.

Strauss and Wellisch (1981) reported cough as being the most troublesome symptom listed by patients. It is interesting therefore that 'reducing cough at other times' was a reported theme in adherence to a physiotherapy programme, and one that is perhaps under-explored by physiotherapists when discussing the relative benefits of a sputum clearance programme.

With regard to the t-test, patients who reported physiotherapy as being very helpful and important to their feeling of well-being had significantly lower lung function in terms of FEV\(_1\) than those who said they found physiotherapy 'not helpful' and 'not important' to their feeling of well being (\( p = 0.0021 \) and \( p = 0.013 \) respectively). The reason for this may be manifold: with declining lung function, visits to clinics and the physiotherapy department increase in frequency and patients tend to become more emotionally dependent on physiotherapy. Patients' responses to the open questions imply that they feel that doing physiotherapy enables them to exert more control over their disease. Those patients reporting physiotherapy as very helpful may feel better afterwards and with less functioning lung the clearance of secretions becomes more important. There was unanimous agreement that all patients felt physiotherapy was very helpful or helpful when they were unwell.

With regard to the factors influencing non-adherence, a lack of time was the most common reason. This supports the finding of Currie et al (1986) in patients with bronchiectasis and Fong et al (1990) in patients with cystic fibrosis. Some of the perceived pressure on time may relate to 56% of the respondents in this study being engaged in full- or part-time work. With this pressure on time, it is essential to help patients in finding the most efficient and effective programmes for them, and to review them regularly. Programmes
individualised for each patient may enhance adherence.

The patients' views and beliefs about exercise were only superficially explored in this questionnaire; 24% of patients felt they could substitute exercise for physiotherapy and these beliefs need to be explored further. Advice on exercise was under-reported as a reason for consulting the physiotherapist at a clinic appointment. Although only one person reported advice on exercise as a reason for attending, 90% of patients reported their beliefs about the benefit of exercise and 46% of patients reported doing more than one hour of exercise each week, but these patients did not perceive physiotherapists as having a role in tailoring exercise programmes for them.

The reasons given for attending physiotherapy out-patient clinics are perhaps disappointing in that 'To check my method of physiotherapy' was a more common statement than 'To discuss any problems or queries'. It is also somewhat surprising that the only reason given by six patients for attending physiotherapy was to obtain a sputum sample. This is a group whose views need to be further sought and explored. Advice on exercise, maintenance of posture and ergonomic considerations featured poorly in this section. Physiotherapists may need to be more proactive if patients are to understand the wealth of information they could access via their physiotherapists. Patients seem to pick and mix the information given to them by physiotherapists. For an example of this, they report 'huffing' as their preference for sputum clearance but not huffing alone or huffing and breathing control as one might think from the literature on sputum clearance (Pryor et al, 1979; Salh et al, 1989) but huffing combined with a variety of other techniques, eg clapping, nebuliser and sport. The views of the nine patients (8%) who felt able to follow physiotherapists' advice 'not often' or 'never', need to be further explored.

Despite literature suggesting that sputum clearance in patients in a clinically stable state can be as effective without an assistant (Pryor and Webber, 1979) 20% of patients in this study reported preferring help most of the time. The major reported reason for this was that they then found treatment less tiring. It is known that some patients have strong beliefs about the benefit of chest clapping (Carr et al, 1995). It may be that because self chest clapping expends energy (Phillips et al, 1994) they prefer to have an assistant for clapping to reduce the effort involved.

Surprisingly there was no relationship between those preferring help and the reported volume of sputum produced. This would have supported the work by Gallon (1991) suggesting an increased rate of sputum clearance when using an assistant and the active cycle of breathing techniques in stable bronchiectatic patients who were large-volume sputum producers. There was no correlation between patients preferring to have an assistant and the severity of lung function.

It was beyond the scope of this study to examine whether and how regularly patients would wish to consult physiotherapists, or to examine whether particularly defined groups of patients (eg copers/non-copers or patients with different locus of control) have disparate views. Further studies need to explore and expand on cystic fibrosis patients' beliefs and views on physiotherapy, exercise, physiotherapists and the different approaches they take, if adherence to treatment is to improve.

**Conclusion**

In this study, reported views and beliefs about physiotherapy and exercise were extremely positive. However, it must be taken into account that nearly half of the sample were non-responders and were not followed up. In essence, physiotherapists can only hope to facilitate adherence to treatment if they can elicit and understand the patients' views and beliefs when negotiating a treatment programme with them and then create an optimum clearance and exercise programme tailored to each individual's needs and beliefs. To this end, physiotherapists and patients need to collaborate in planning a treatment programme.

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References

The Neuromuscular Approach to Efficient Handling and Moving

Video 1: Concept and philosophy principles. 38 minutes. £120.
Video 2: Conditioning movements. 48 minutes. £120.
Video 3: Facilitatory handling. 60 minutes. £120.
Audio cassette: Conditioning programme. 80 minutes. £7.

Complete set £275, post free. Consultants Lesley Crozier MCSP DipTP, Sheila Cozens MCSP LiAc MBAcC. 1996. Available from Asian Studios Ltd, 26 Standen Place, Holbrook, Horsham, West Sussex RH12 7JS.

This series of three videos and a cassette forms a comprehensive aide mémoire for anyone attending or who has attended training on the neuromuscular approach to efficient movement.

From the outset it is made clear that the approach is not a set of techniques for manual handling but is a principle-based concept of human movement which can be applied to manual handling of loads.

The principles of efficient movement are clearly and effectively explained using everyday situations and tasks. This not only helps to make the principles easy to understand, it illustrates their application in a variety of situations.

The second video deals with specific and patterning conditioning movements, their relationship, and the rules governing their performance. It emphasises not only the importance of these movements from a physiological and safety point of view but reinforces the fact that these movements are an integral part of the neuromuscular approach. A clear demonstration is given of the movements, adjustment to skin loading, and how to identify and resolve potential problems.

The final video demonstrates how the principles and pattern of movement can be applied in the manual handling of people. There is a clear demonstration and explanation of various holds and how these, together with the principles and patterns of movement, can be employed to move patients in a variety of situations with or without equipment.

The videos are clearly not intended to be prescriptive in their instruction but set out to describe and reinforce a set of principles which can be translated into a pattern of movement, which can then be applied to handling tasks.

This is a well-made video set which uses a nice combination of real-life situations, animation and straightforward demonstration to illustrate its point.

I would recommend it to anyone who has undertaken training in the neuromuscular approach and who intends to continue its use.

Aileen M Hunter BEd MCSP

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