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Adherence to Chest Physiotherapy in Adults with Cystic Fibrosis

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Abstract

Chest physiotherapy (CP) is seen as a cornerstone of Cystic Fibrosis (CF) treatment. However, previous studies have suggested that adherence to CP is low. This study of adults with CF ($N = 563$) investigated CP adherence and associated factors. Only 29.5 per cent reported undertaking daily CP. Predictors of adherence included problems with fitting CP into lifestyle, a perception that CP does not help, physical consequences of CP, doing exercises instead and doing CP as and when necessary. These variables accounted for 45 per cent of the variance in adherence. Content analysis revealed a number of themes related to adherence to CP. Future studies should explore the benefits of daily CP and attempt to devise simple interventions to maximize adherence to CP.

Keywords

- *adherence*
- *chest physiotherapy*
- *cystic fibrosis*

Introduction

CYSTIC FIBROSIS (CF) is a genetic disorder resulting in the blocking of chloride transport through cells. This results in the production of abnormal sticky secretions and subsequent damage to several organs in the body, including the lungs, liver, pancreas and intestines (Welsh & Smith, 1995). Twenty per cent of adults with CF have associated diabetes mellitus (Conway, 1996). The incidence of the disease is estimated at 1:3500 live births, making it the most common autosomal recessive genetic condition (Lowton, 2003). In recent years, medical and technological advances such as early diagnosis, specialist care, more effective treatments and organ transplantation, have resulted in a rise in the median international survival age from eight years in 1974, to 21 years in 1998 (Fogarty, Hubbard, & Britton, 2000). The median predicted survival in 2004 was approximately 32 years (Yankaskas, Marshall, Sufian, Simon, & Rodman, 2004). Elborn, Shale and Britton (1991) have suggested that the median survival of babies born with CF in 2000 will be 40 years, but this is contentious (see Addy, 1992). The overall figures for the increased number of people with CF who are now surviving into and past their own child-bearing years mask wide variations in survival rates across and within countries, however, and the fact that women are significantly more likely to die at a younger age than the median age for men (Fogarty et al., 2000). The reasons for these variations are not clear and are probably multifactorial. Variations in patterns of adherence to treatment regimens may be one factor.

Poor adherence to treatment is well recognized, and significantly contributes to treatment failures in medical interventions. The level of non-adherence in the general population varies depending on the patient population, medical condition, form of treatment and the definition of adherence. However, an average of around a third of patients fail to adhere to the recommended therapeutic regimen and this increases to around 50 per cent in chronic illnesses (see Myers & Midence, 1998a). Although the relationship between adherence to the CF regimen and disease progression is still a matter of debate, it is likely that, as in other chronic conditions, poor adherence results in more acute episodes and hospital admissions, and possibly,

premature death (DiMatteo, Giordani, Lepper, & Croghan, 2002).

Why do people fail to adhere to crucial treatments in this serious and potentially fatal disease? Generally, there is little association between seriousness of an illness and adherence to treatment. For example, a number of adherence studies in patients who have received an organ transplant indicate that these patients are just as likely to be non-adherent as patients with less severe illnesses, even though non-adherence to the medical regimen can lead to rejection of the organ or death of the patient (see Myers & Midence, 1998a for a review).

Adherence has been shown to vary with different aspects of the CF regimen, with overall high rates for medication and low rates for chest physiotherapy (CP) (e.g. Abbott, Dodd, Bilton, & Webb, 1993; Kettler, Sawyer, Winefield, & Greville, 2001; Myers & Myers, 1999). For example, Myers and Myers (1999) compared various adherence behaviours that had been rated by people with CF on a seven-point scale. The neutral midpoint of four (i.e. average) was taken to indicate neither adherent nor non-adherent behaviour. Adherence scores significantly above the midpoint were called 'high adherence behaviours' and adherence scores significantly below the midpoint were called 'low adherence behaviours'. Results indicated a range of adherence behaviours were significantly higher than average and were therefore considered high adherence behaviours—antibiotics, other medication, pancreatic enzymes, vitamins and nebulizers. High calorie meals and exercise did not significantly differ from the average. CP was significantly lower than the average and was the only treatment considered to be a low adherence behaviour.

Reasons for adherence problems in CF have been explored in various studies. Management of the condition from day-to-day places a very high level of demand on adults with CF. Kettler et al.'s (2001) article draws attention to the high level of the demand placed on patients by day-to-day management of CF by a regimen which is complex and which involves a number of different treatments. These include: daily CP and exercise to clear secretions from the lungs, enzymes and vitamin supplements to ensure adequate nutrition and oral and nebulized medication to assist lung function and decrease

the bacterial load in the lungs (Conway, 1996), and in some cases nocturnal ventilation and feeding by gastrostomy (Abbott et al., 1993).

Respiratory failure is the cause of death in over 90 per cent of cases (Ramsay & Marshall, 1995). CP is a treatment that is an integral part of management of CF and needs daily commitment (Holland, Denehy, Ntoumenopoulos, Naughton, & Wilson, 2003). CP is thought to be one of the most important treatments in maintaining lung function, and is also the most time-consuming and demanding. CP is typically carried out twice a day, but may be increased to four times if necessary. Techniques and time taken over CP vary, but the aim is to promote the coughing up of sputum to keep the airways clear. There are few studies on the reasons for the low rate of adherence to CP. Conway, Pond, Hamnett and Watson (1996) found the major reasons given for omitting CP were the time and commitment demands, a preference for exercising instead and the belief that it is ineffective. Is severity of CF related to CP adherence? Objective measures of disease severity were not related to adherence to CP in Abbott et al.'s (1993) study. However, adherence with CP was related to reporting an immediate benefit (as opposed to no improvement), producing large amounts of sputum and having help with CP. Moreover, although adherence with CP was lower than that with enzyme and exercise, 67 per cent of participants considered it to be 'about right'. Oerman, Swank and Sockrider (2000) showed an overall positive relationship between subjective rating of severity and both adherence to CP and satisfaction with it. However, there were differences in ratings for satisfaction, convenience, efficacy and comfort between different types of CP. The more traditional method and most widely used method, postural drainage, percussion and vibration (PDPV), which is very time-consuming, needs a skilled helper and has a number of unpleasant side-effects, was outranked by newer self-administered methods which are shorter in duration and with fewer side-effects. Commitment to adherence is thus influenced by a number of individual preferences and judgements, not necessarily related to objective severity of disease.

There are inter- as well as intrapersonal influences on treatment decisions and some aspects

of outcome. Specialist treatment centres may have an impact on outcome via close monitoring and improved adherence. Mahadeva et al. (1998) have shown better clinical outcome (improved nutritional status, FEV₁ and chest x-ray film scores) in children and adults attending specialist CF centres, but they did not report whether higher age-at-death rates were also associated with such care.

That patients make their own judgements about when and how to adhere to treatment regimens is not new and is not confined to CF (see Myers & Midence, 1998b). Some decisions not to adhere may be considered rational when there is uncertainty about the perceived benefit of treatment and the process of treatment is lengthy and unpleasant. There is a clear need for further studies about the relative efficacy (long- and short-term) of traditional and newer treatments for CF. At the very least, patients could then be helped to make well-informed choices. There is also an urgent need for more detailed studies of how and why patients make decisions about adherence, so that those who care for them and advise them can make well-informed decisions about the most effective delivery of care.

Therefore, the aim of this study was to explore adherence to CP in adults. A previous study, mentioned earlier, which found that self-reported CP adherence was lower than any other adherence behaviour, was limited as data came from one clinic with only 32 participants (Myers & Myers, 1999).

The current study looked at CP in more detail using a large sample. We wanted to see if we could replicate the previous findings (Myers & Myers, 1999) and in addition we looked at reasons for non-adherence using both quantitative and qualitative methodology.

Method

Participants

Questionnaires were sent to everyone over 18 years with CF on the UK's Cystic Fibrosis Trust mailing list. There were 563 usable replies (39.8 per cent response rate). There were 310 females and 253 males, mean age 27.85 years, range 18 to 66. Median age was 26 years. A total of 82.7 per cent reported that they attended a CF centre. This was part of a larger study investigating lifestyle of people with CF.

Measures

A questionnaire was developed for the study, with both closed and open-ended questions, to explore aspects of adherence to CP. In order to minimize social desirability effects in this self-report measure, instructions were framed such that variations in how and when people adhered to their treatment regimens was taken as the norm. For example, the beginning of the questionnaire states:

Many people we have talked to say that they look after their CF in a way that suits them, rather than following recommendations to the last detail. We are interested in how you look after your CF and how you feel about the different treatments.

This wording was taken from other studies on adherence and chronic illnesses (e.g. Cooke, Myers, & Derakshan, 2003; Griva, Myers, & Newman, 2000).

Adherence to CP This was measured with one item: 'physiotherapy is part of my daily routine', rated on a five-point Likert scale: 1 (never); 2 (hardly ever); 3 (sometimes); 4 (almost always); and 5 (always). In addition, there was a box to tick if physiotherapy was not part of the treatment.

Reasons for non-adherence Participants were told: 'the next questions are about physiotherapy. Below are a number of reasons people with CF say they may not do their physiotherapy as often as recommended (usually twice each day)'.

There were 17 reasons for not doing CP, rated on a four-point Likert scale: 1 (not at all true); 2 (slightly true); 3 (moderately true); and 4 (very true). These were taken from previous literature and talking to people with CF. Items are listed in Table 1. Participants were then asked for (to indicate) the most important reason why they might not do their CP, from the 17 items.

Contact with physiotherapist Participants were asked if they saw a physiotherapist: (a) to consult with; (b) for hands-on treatment.

Qualitative information Participants were asked to write about reasons for doing/not doing their physiotherapy exercises.

Severity Objective severity is often measured by FEV₁, FVC (both are lung function tests), chest x-ray score, etc. (Abbott et al., 1993). In this study, objective severity was measured by the number of chest treatments currently being used from the following: oral antibiotics; nebulized antibiotics; intravenous antibiotics; oral steroids; inhaled steroids; inhaled bronchodilators; nebulized bronchodilators; dnase.

Subjective severity was measured with the item: 'Please rate how severe you consider your CF to be by circling a number between 1 (very severe) and 10 (not at all severe), which you feel best corresponds to your health.'

Demographic information Participants were asked to indicate their age and gender and whether they attended a CF centre.

Results

The quantitative data were analysed by the first author (LM) and the qualitative data were analysed by the second author (SH). For quantitative analyses, significance levels were set at $p < .01$ due to large number of participants to minimize type 1 error.

Table 1. Reasons for not doing CP

Reason	Mean (SD)
It needs a lot of commitment	3.22 (1.03)
No time in the morning/generally	2.47 (1.23)
I do physiotherapy as and when necessary	2.46 (1.23)
It is a constant reminder of my CF	2.39 (1.23)
I'm too tired in the evening	2.38 (1.15)
It's too much effort	2.31 (1.07)
I do exercises instead	2.31 (1.17)
I resent having to do it	2.26 (1.20)
I don't like admitting a sick role	1.99 (1.18)
It spoils my quality of life	1.93 (1.08)
I tend to forget	1.92 (1.22)
My CF is not severe enough	1.77 (1.04)
I don't produce sputum	1.77 (1.05)
It's embarrassing	1.85 (1.09)
Physiotherapy makes no difference	1.69 (0.97)
It makes me vomit	1.58 (0.85)
I feel too ill and need assistance	1.42 (0.75)

Quantitative analyses

Adherence question Out of the 563 participants, 522 (92.7%) indicated that daily CP was part of their prescribed treatment. However, only 29.5 per cent reported that CP was always part of their daily routine, i.e. that they were always adherent. In total, 14.5 per cent reported being almost always adherent, 19.4 per cent said that they were sometimes adherent, 17.9 per cent reported that they were hardly ever adherent and 11.4 per cent said that they were never adherent. A one-way analysis of variance (ANOVA) indicated that the adherence score was not related to gender $F(1, 520) = 2.64$, NS, or whether patients attended a CF centre $F(1, 520) = 0.11$, NS. A Pearson correlation indicated that adherence was not related to age ($r = .05$, NS); subjective severity ($r = .11$, NS) or objective severity ($r = .16$, NS).

Physiotherapist A total of 65.9 per cent of participants said they consulted with a physiotherapist. One-way ANOVA indicated that this was significantly related to adherence, $F(1, 511) = 10.24, p < .001$. Only 26.1 per cent had hands-on physiotherapy administered by a physiotherapist and this was not related to adherence, $F(1, 508) = 3.75$, NS.

Reasons for non-adherence Items, means and standard deviations can be found in Table 1. 'It needs a lot of commitment' was the most highly rated reason. Other highly rated reasons were, 'no time in the morning/generally', 'I do physiotherapy as and when necessary', 'It is a constant reminder of my CF', 'I'm too tired in the evening', 'It's too much effort', 'I do exercises instead', 'I resent having to do it'.

The most important reason for not doing CP Ratings can be found in Table 2. Three reasons were rated more important than the others: 'No time in the morning/generally' (20.3%), 'I do exercises instead' (19.0%) and 'I'm too tired in the evening' (10.6%).

Factor analysis was performed on scores from the 17 items using a principal component analysis with varimax rotation. Factors whose eigenvalues were one or greater were retained and loadings greater than 0.5 were considered significant. Three items were removed as they did not load on any one factor. These were: 'It

Table 2. The most important reason why participants may not do CP

Reason	%
No time in the morning/generally	20.3
I do exercises instead	19.0
I'm too tired in the evening	10.6
I tend to forget	6.6
It's too much effort	6.4
I don't produce sputum	5.7
It is a constant reminder of my CF	5.1
It needs a lot of commitment	4.6
I resent having to do it	3.1
I do physiotherapy as and when necessary	2.9
My CF is not severe enough	2.9
I feel too ill and need assistance	2.6
It spoils my quality of life	2.2
It's embarrassing	2.2
Physiotherapy makes no difference	2.2
It makes me vomit	1.8
I don't like admitting a sick role	1.4

needs a lot of commitment', 'I do exercises instead', 'I do CP if and when necessary'. This produced four factors: Factor 1 'emotional consequences of CP', Factor 2 'CP does not help', Factor 3 'fitting CP into lifestyle' and Factor 4 'physical consequences of CP' (see Table 3).

Table 3. Factor structure of reasons for non-adherence

Factor
Factor 1: emotional consequences of CP
I don't like admitting a sick role
It's embarrassing
I resent having to do it
It is a constant reminder of my CF
Factor 2: CP does not help
Physiotherapy makes no difference
My CF is not severe enough
I don't produce sputum
Factor 3: fitting CP into lifestyle
I tend to forget
No time in the morning/generally
I'm too tired in the evening
Factor 4: physical consequences of CP
It's too much effort
It makes me vomit
I feel too ill and need assistance
It spoils my quality of life

Cronbach's alpha indicated satisfactory internal consistency: Factor 1 (0.78), Factor 2 (0.70), Factor 3 (0.69), Factor 4 (0.71).

Explanations for non-adherence To investigate possible reasons for non-adherence/adherence to CP we undertook a hierarchical multiple regression, with demographic information (age, gender, attendance at CF centre) in step 1, subjective and objective severity measures in step 2, and then the four factors, plus the three individual items that did not load on any factor in step 3. This model explained 45 per cent of the variance in adherence to CP. Significant predictors were two individual items: 'I do exercises instead' and 'I do CP if and when necessary', Factor 2: 'CP does not help', Factor 3: 'fitting CP into lifestyle' and Factor 4 'physical consequences of CP' (see Table 4).

Qualitative data

Participants were invited to write their own additional reasons for non-adherence to CP in a free text format. A total of 195 participants (34% of sample) chose to do so. This sub-set was compared with the whole sample on a range of variables. They did not differ from the main sample on most variables, but overall reported more current chest treatments (our measure of objective severity), ($F(1, 554) = 9.09, p < .001$) and there were more women (121) than men (74), ($\chi^2 = 8.78, d.f. = 1, p < .005$).

Table 4. Multiple regression of non-adherence on reasons for possible non-adherence to CP

	Adjusted R ² 45%	Beta
Gender		0.03
Age		0.05
Objective severity		0.03
Subjective severity		0.01
Commitment		-0.04
I do exercises instead		-0.18***
I do CP as and when necessary		-0.26**
Factor 1: emotional consequences of CP		-0.02
Factor 2: CP does not help		-0.38***
Factor 3: fitting CP into lifestyle		-0.21***
Factor 4: physical consequences of CP		-0.10*

*** $p < .001$; ** $p < .01$; * $p < .05$

All the comments were transcribed verbatim and coded line by line. Identifying codes included participant number, line number, age, gender, severity index. The transcribed comments were subject to content analysis. They were read and re-read, and any meaningful phrases or sentences were highlighted as potential units of coding. Coding was exclusive; each unit was coded under one theme. Some people gave several responses, however, resulting in several codes. The margins were annotated with emerging themes, which were then inspected for commonalities. Six clusters of related concepts were identified from this process and given brief descriptive labels. An additional two themes were derived from responses by people who chose to write their reasons for adherence rather than non-adherence. All coded units were grouped under the eight themes, which are reported below, together with typifying units of coding, taken verbatim from the transcripts.

Theme 1: the impact on life of the time CP takes (n = 24) This included all responses indicative of the potential disruption to daily life caused by the time CP takes. It does not include disruption caused by other aspects of CP.

... with working full time and trying to lead a normal life, physio comes down the list. I could spend the day treating CF and not living a full life. (participant 297)

I'm a bloke—if I have to be somewhere at 9 am then I have to get up 2.5 hours earlier to incorporate my treatment as well as many things. Sex? Wank? Shower? Physio? Nebulized drugs, exercise, eat. It's hard to do everything. (participant 502)

This theme is typified by the conflict between the time needed for 'normal' daily life and the time taken up by CP. 'Normal' things take precedence.

Theme 2: social embarrassment associated with CP (n = 8) This theme included all responses indicative of shame associated with those aspects of CP thought to be actually or potentially distasteful or aversive to others. It does not include aspects distasteful to oneself.

If staying at a stranger's house it looks as if you are on death's door if you start phlegming

and go bright red through strained coughing. (participant 501)

I have to do it while my partner's still in bed in the morning and before he's back from work at night. He thinks it's horrible and I feel embarrassed. (participant 300)

I choose not to in company . . . not wanting to make others feel ill. (participant 262)

The socially unacceptable effects of CP, such as coughing up phlegm, are considered to make it 'taboo' in casual and some close relationships.

Theme 3: doing CP is a constant reminder of illness ($n = 7$) This theme includes all responses indicative of the threat posed by being repeatedly confronted with evidence of one's sick self.

. . . reduced to coughing and sputtering and possible vomiting. Distasteful and 'out of control'. (participant 523)

I resent that I have to cough up sputum at my age. It is disgusting and normally associated with people who are sick and old. (participant 419)

I don't want to do it because I don't want to face what I have and how it makes me feel. (participant 439)

I just feel I am a total write-off and am sick of always being ill. (participant 76)

The unwelcome reminders of ongoing disease produced by CP are aversive and can be avoided by omitting the treatment.

Theme 4: doubts about the efficacy of CP/makes me feel worse ($n = 11$) This theme includes all responses indicative of doubt about the positive—or indeed, any—effects of CP. It does not include responses concerning negative effects.

Treatment like CP and nebulizers do not have an immediate or noticeable effect so I don't really do them. (participant 216)

Feels a waste of time. (participant 399)

These responses suggest that some people with CP are unconvinced that they benefit from CP, at least in the short term.

Theme 5: using alternative strategies ($n = 14$) This theme includes all responses indicative of an active, chosen alternative method of maintaining lung function and clearing the airways.

I do weights and running instead. It is actually better than CP. (participant 80)

Exercise brings up my sputum better than CP. (participant 279)

I feel I get more out of exercise due to enjoyment. (participant 156)

These are active alternatives to CP rather than passive non-performance of the regime, suggesting that the need for treatment is acknowledged but the form it takes has been re-created by these participants.

Theme 6: feeling well and not in need of CP ($n = 17$) This theme includes all responses indicative of CP being seen as redundant because the participant feels well or has had a transplant.

I feel as if I can get away with not doing it as I am well and the resultant effects of not doing it are not short term, immediate. (participant 414)

My chest is relatively clear. (participant 305)

I don't do physio any more as I have had a transplant. (participant 351)

Some people, who have very slight symptoms or who produce little mucus or who have long periods of wellness or have had transplants, do not feel the need to perform CP.

Theme 7: adherence to physiotherapy is essential to well-being and life itself ($n = 37$) This theme includes all responses indicative of adherence to CP no matter whether symptoms are present or not. It does not include responses indicative of adherence when CP is experienced as aversive.

I've always done CP even when very fit, that's why I'm 35 and still alive; it's as simple as that. (participant 51)

I would never not do CP as this is one of the most important ways to keep healthy. (participant 91)

I'm glad to be able to do it so I can just live on to fight another day. (participant 118)

Some of these respondents are well and/or have had transplants, but have incorporated CP into their daily routines so completely that they perform it irrespective of their state of health.

Theme 8: CP is a problem but a price worth paying ($n = 14$) This theme contains all responses indicative of adherence to CP in spite of negative feelings about it.

Always do it even though I hate it. (participant 69)

I'm extremely diligent about doing CP 2.5 hours a day, *but* it is the bane of my life. (participant 371)

These responses suggest that, in these participants, CP is not easily incorporated into their lives, as it causes negative feelings, but this is not associated with non-adherence—they get on with it.

During the process of analysis, it became clear that the sub-sample of those who chose to give their own additional reasons for their non-adherence/adherence to CP reasons was made up of three distinct groups: always adherers ('I never miss a session of CP'); never adherers ('CP is too much time and hassle'); and conditional adherers ('I may not do CP when I'm coughing a lot anyway/hung over/have overslept'). The identifying codes allowed exploration of the severity status of members of the three groups, using number of current treatments (objective indication of severity) and self-report of how the participant felt they were compared with other similar people with CF. A further analysis was carried out on these three groups (see following section).

Relationship between qualitative and quantitative data

We investigated differences between adherers, ($n = 42$) sometime adherers ($n = 44$) and never adherers ($n = 53$) as identified through the qualitative analyses. Group differences in the means were tested for using one-way ANOVA. Newman-Keuls tests were used for all post-hoc comparisons, with significance levels set at $p < .05$. The three groups were compared on age, gender, whether they attended a CF centre,

subjective severity, objective severity, reasons for not doing CP, It needs a lot of commitment, I do exercises instead, I do CP if and when necessary.

There were significant differences for adherence, $F(2, 120) = 54.52, p < .001$, with all three groups significantly differing from each other in the expected direction. There were significant differences for 'I do exercises instead', $F(2, 117) = 11.18, p < .001$, with always adherers reporting doing exercises significantly less often than both sometimes and never adherers. There was a significant difference for 'I do CP if and when necessary', $F(2, 117) = 11.41, p < .001$, with always adherers scoring significantly lower than both sometimes and never adherers. For Factor 2 'CP does not help' and Factor 3 'fitting CP into lifestyle' all three groups differed from each other in the expected direction ($F(2, 117) = 20.28, p < .001, F(2, 117) = 29.77, p < .001$ respectively). For Factor 4, 'physical consequences of CP' always adherers scored significantly lower than both sometimes and never adherers, $F(2, 117) = 11.08, p < .001$.

There were no significant differences for age, $F(2, 135) = 2.18, NS$. 'It needs a lot of commitment', $F(2, 114) = 3.58, NS$, objective severity $F(2, 132) = 3.31, NS$, subjective severity, $F(2, 134) = 1.67, NS$ and Factor 1 'emotional consequences of physiotherapy' $F(2, 110) = 3.61, NS$. Chi-square indicated that there were no significant differences in gender, ($\chi^2 = 1.56, d.f. = 2, NS$) and whether they attended a CF centre, $\chi^2 = 0.67, d.f. = 2, NS$. Always adherers were more likely to consult with a physiotherapist than both sometimes and never adherers, $\chi^2 = 8.33, d.f. = 2, p < .005$, but there were no differences for hands-on treatment from a physiotherapist, $\chi^2 = 0.38, d.f. = 2, NS$.

Discussion

This study was designed to explore aspects of adherence and non-adherence to CP from responses to both scaled and open-ended questions. Traditionally, it is believed that CP for CF needs daily commitment (see Cystic Fibrosis Trust, 2002; Holland et al., 2003). Yet there was very low self-reported adherence, with only 29.5 per cent indicating that CP was always part of their daily routine. Research has shown that people usually overestimate self-report measures

of adherence (see Myers & Midence, 1998a), so the real figure may in fact be lower. These findings replicate and extend previous research on adults with CF, indicating low levels of adherence to CP (e.g. Myers & Myers, 1999) and also stress the importance of understanding non-adherence to CP.

In addition, 7.3 per cent of participants indicated that CP was not part of their treatment. This finding needs to be investigated in future studies. It may be that these people with CF are being non-adherent, or it may be that they have been advised by their CF team that they do not need to do CP. If the latter is the case, it is against current recommendations, and it is important to know the basis of such decisions.

Many participants reported seeing a physiotherapist to consult with (65.9%), while having hands-on treatment was reported by only 26.1 per cent. This is probably because few adult CF patients will be given regular CP by a trained professional; most will be self-administered or carried out by a relative. Adherence to CP was related to consulting a physiotherapist, but not having hands-on treatment. This suggests a pivotal role for physiotherapists as consultants. Further studies should examine the content of these physiotherapist-patient interactions, to identify beneficial themes with the aim of implementing them in a simple intervention aimed at physiotherapists.

This study has confirmed findings in a wide range of other studies of adherence to care regimens in chronic disease: patterns of adherence vary according to factors other than disease characteristics (see Myers & Midence, 1998b). As in previous studies on CF neither objective severity of the condition (Abbott et al., 1993), nor demographic characteristics (Myers & Myers, 1999) predicted adherence to CP. Rather, problems with fitting CP into lifestyle, a perception that CP does not help, the physical consequences of CP, doing exercises instead and doing CP as and when necessary, taken all together account for 45 per cent of the variance. Emotional consequences (embarrassment, not liking admitting the sick role, resentment, constant reminder of illness) are not predictive. These results from scaled responses were closely mirrored by themes derived from the open-ended questions and suggest that non-adherence is intentional and that there are

rational and practical reasons why people might not adhere. Surprisingly, subjective severity was not related to adherence. This finding may relate to the doubts about the efficacy of CP and/or the burdens it imposes, expressed by participants. This needs further investigation.

The time taken up by CP was a reason for not carrying out CP in both quantitative and qualitative responses. 'No time in the morning/generally' (20.3%); as was the physical demand: 'I'm too tired in the evening (10.6%)' (theme 1 in the content analysis). Shorter and less onerous techniques could replace CP (e.g. the Flutter: de Lima, Duarte, Neto, Abe, & Gastaldi, 2005). If such techniques were of proven efficacy, this might have a positive impact on adherence.

Exercise was an important reason for not doing CP, with nearly a fifth of participants choosing to replace CP with exercise. No study has yet been reported in which exercise was tested against CP; those few considered by Bradley and Moran (2002) looked at CP alone or CP plus exercise. While there might be ethical objections to a 'no CP' condition in such a study, if very poor adherers were recruited it could be argued that they would be undertaking some treatment as opposed to little or none. In addition, recent treatment guidelines for physiotherapists include recommendations that exercise should be included as part of the CF therapeutic regimen—tailored to the individual taking into consideration disease severity, level of fitness and patient's preference to exercise activities. With such large numbers of people opting for exercise instead of CP and these recent recommendations to include exercise in the daily routine, it is more than time its effectiveness was evaluated systematically.

The mixture of qualitative and quantitative methods in the questionnaire was designed to collect as much scalable data as possible, but also to give participants the opportunity to put their experiences into their own words and elaborate on their responses to the rating scales. On the whole the two sets of data, quantitative and qualitative, which were analysed independently, complemented each other well. The qualitative data also identified three sub-groups: always adherers, sometimes adherers and never adherers. They did not differ from each other in terms of age, gender, objective severity or

subjective severity. Between-group differences in the adherence predictors were in the expected direction. The themes developed from the free text responses support the quantitative findings, and also open up other areas of interest. For example, in the 'always-adherer' group, there were people carrying out long periods of CP regardless of severity of their symptoms. This group scored lower on 'I do physiotherapy as and when necessary' than sometimes/never adherers, suggesting that they were in a set routine rather than a rational programme which could be changed to meet their changing needs. They also reported doing exercises significantly less than the sometimes and never adherers, which again suggests that they are not undertaking alternative ways of treatment which might have a lesser impact on their lives but could be equally effective in controlling their symptoms. In the light of the recommendation to include exercise (Cystic Fibrosis Trust, 2002), this is a cause of concern. It may be regarded as equivalent to self-inflicted over-medication, and is worthy of further investigation. At the other end of the scale, the never-adherer group included not only people with low levels of sputum, who may need less CP, but others who needed, but did not carry out, CP. They gave a range of reasons for non-adherence, as did the sometimes-adherers, some of which could be addressed by treatment regimes tailored to their individual needs—for example, if two long sessions a day are not tenable within their lifestyle, other more suitable methods could be discussed with them by their CF physiotherapist (Cystic Fibrosis Trust, 2002).

There were methodological limitations in the study. Self-report has the potential to be influenced by social desirability biases. We attempted to minimize the impact of such an influence by framing the questionnaire in such a way that non-adherence was accepted as the norm—we were interested in individual types of non-adherence and reasons for them.

The response rate was lower than ideal, but it produced a sample size of 563 with a range of severity and the profile of responders matched the overall profile of the CF Trust's database. By using the Trust's mailing list, we were potentially introducing bias by sampling from a sub-set of people with CF who might have been more active in self-management. However, all similar

studies are limited to those who choose freely to participate, and we can but acknowledge this as a limitation. The median age of the sample is a little lower than that suggested by Lowton and Gabe (2003) but the range was from 18–65, which is satisfactorily broad.

We note differences between the main group and those who chose to give qualitative information; there were proportionally more women and people with higher objective (but not subjective) severity scores than in the main sample. The written responses were also necessarily brief, and there was no opportunity to probe. Although in this study severity did not impact on adherence, in a future study, in-depth interviews with people of a range of severities and equal numbers of men and women should be carried out in order to gather richer data from a more representative group.

In conclusion, regularly clearing mucous secretions by the use of CP and medication is thought to be of crucial importance in preventing recurrent infections and irreversible damage to lung tissue. However, the long-term effectiveness of CP in the respiratory management of CF has proved difficult to determine. Studies have tended to be small numbers, short-term or single case, and for ethical reasons have not included control (no-treatment) conditions (van der Schans, Prasad, & Main, 2002). Nevertheless, a systematic review demonstrated short-term benefit from airway clearance (van der Schans et al., 2002). Some evidence for long-term benefit is discussed by Abbott, Dodd, Gee and Webb (2001), but to date, there is no conclusive finding of a relationship between adherence to CP and long-term outcome.

Studies on the benefits of exercise in helping to maintain pulmonary function have similar limitations: it may be that adding physical training to the regime helps to prevent deterioration in pulmonary function, but more extensive and better-controlled studies are needed in order to demonstrate any effect convincingly. In recent years, less time-consuming and onerous techniques have been added to, and have sometimes replaced CP (see Cystic Fibrosis Trust, 2002). They are often more acceptable to patients and may therefore increase adherence, but as yet they have not been evaluated adequately. Patients are, nevertheless, likely to be advised to perform CP on a daily basis as an essential part

of their treatment. In the face of the evidence to date, those who choose not to adhere because they do not perceive benefit and/or find the regime too time-consuming and disruptive of their lives, may be making a rational decision, and those who perform twice-daily CP no matter what, may not be. Until the crucial studies have been carried out, the best advice for people with CF may be that they should carry out regular clearance of secretions, in a way that suits their lifestyles. This will involve regular contact with specialist health care professionals in planning and monitoring the agreed regime and its effectiveness.

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