A survey of exercise testing and training in UK cystic fibrosis clinics

D. Stevens, P.J. Oades, N. Armstrong, C.A. Williams

Abstract

Background: Exercise testing is a valuable prognostic tool and exercise training has many health benefits in cystic fibrosis (CF). The objective of this study was to survey the provision of exercise testing and training in UK CF clinics.

Methods: A three-page questionnaire was used to determine the extent of, scope and importance assigned to exercise testing and training.

Results: Data from returned questionnaires showed that 38.9% of paediatric and 27.8% of adult patients had performed an exercise test in the preceding 12 months, most as part of an annual review process. Pulmonary rehabilitation programmes were accessible in only 31.3% of clinics, and only 26.0% provide exercise training programmes. When assigning importance for exercise testing on a scale from 1 ‘not important’ to 5 ‘very important’, the mean and median respondent scores were 3.5 and 4.0, respectively, and for the importance of training were 4.0 and 4.0, respectively.

Conclusions: Despite the level of importance given to exercise testing and training by healthcare providers, exercise is underused as either an assessment tool or therapeutic intervention in the healthcare of patients with CF in the UK.

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Keywords: Exercise; Healthcare; United Kingdom; Children; Adults

1. Introduction

Exercise performance represents an integration of the cardiopulmonary, loco-motor and metabolic systems. Psychological wellbeing and quality of life are inherently linked to an individual’s physical capability. Consequently, in a multi-system disease such as cystic fibrosis (CF) the assessment of exercise tolerance is clinically relevant. Indeed, aerobic fitness measured by peak oxygen uptake (VO2peak) during maximal exercise is a strong predictor of survival [1–3]. In patients with mild disease more sophisticated testing measuring pulmonary gas exchange during peak performance may detect abnormalities in early disease [4].

Pulmonary rehabilitation (PR) is an intervention for patients with symptomatic chronic respiratory disease limiting their daily life activities. Its therapeutic role in chronic obstructive pulmonary disease (COPD) for exacerbations and chronic limitation is well established. More strenuous exercise training requires engagement in a schedule of vigorous physical activity and in CF may increase aerobic fitness [5,6], decrease the rate of decline [7], or even improve lung function [8] and improve quality of life scores [9]. A Cochrane review reported the benefits of training programmes in CF including help in the management of CF related diabetes mellitus, delay the onset of osteoporosis, decreased anxiety and improved body image [10].

The UK CF Trust standards for clinical care (2001) recommend that annual exercise testing and training should be undertaken, but no details are provided [11]. The objective of this study was to identify and quantify the scope of exercise testing and
training used currently in UK CF clinics, and to determine the importance assigned by clinic staff.

2. Methods

Questionnaires were sent to 186 UK CF clinics (137 paediatric and 49 adult) in 2008. These were identified from the South and West CF Carers Regional Directory 2007 [12]. Centres were asked to confirm whether they were specialist centres, [i.e., staffed by a multidisciplinary team with appropriate expertise, usually caring for a minimum of 100 patients and providing comprehensive access to medical sub-specialties and clinical investigations according to UK standards [11]] or shared care clinics which are smaller and where patient care is supervised, supported and reviewed at least annually by a networked specialist centre. The three-page questionnaire requested information on the number of patients, the professional role of the respondent, whether exercise testing was used to evaluate patient health, equipment available, type of tests used (specific protocols for cycle and treadmill testing, however, were not requested), reasons for conducting testing, and the number conducted for those reasons in the preceding 12 months. Also requested was who within the multi-disciplinary team (MDT) supervised tests, whether availability of personnel, facility or equipment limited testing, and enquired as to what would enhance testing at the clinic. Information was requested about who within the MDT discussed exercise activity with patients, how often and the nature of advice given. Availability and nature of PR and training programmes were sought.

The importance assigned to exercise testing and training was canvassed and quantified by a visual-analogue scale ranging from 1 ‘not important at all’ to 5 ‘very important’.

2.1. Ethical approval

The NHS Research Ethics Committee advised that as the study was a survey on healthcare provision, an ethical review was not required.

2.2. Statistical analysis

Frequencies and descriptive statistics were used to analyse data using the Statistical Package for Social Sciences (SPSS; version 11.0, Chicago, IL).

3. Results

Questionnaires were returned from 96 clinics (response rate 51.6%). Returned questionnaires were completed by clinicians (68.8%), physiotherapists (26.0%) and CF clinical nurse specialists (CNS) (5.2%).

Our survey showed that 51 (53.1%) of responding CF clinics use exercise testing to evaluate patient health. Over a 12 month period in specialist centres 1440 and in shared care clinics 266 exercise tests were conducted. These results reveal that 43.3% and 28.9% of children attending paediatric specialist and shared care clinics, respectively, had undergone a test in the preceding 12 months, compared to 26.8% of adults in specialist and 50.4% in shared care clinics. Data in Table 1 show the availability of equipment for testing and data in Table 2 show the type of tests used. Respondents from 45 clinics stated that the primary reason that exercise testing was limited was due to resource availability. Reasons included lack of personnel or their time (24.0%), lack of facility and/or equipment (13.5%) and lack of both of these (9.4%). On-line supplemental data accompanying this article presents the reasons for exercise testing and which members of the MDT supervise the tests (Supplementary data A), and individual subjective respondent comments to enhance exercise testing at clinics (Supplementary data B).

Overall, 82.2% of clinics discuss exercise activity at every appointment. In 78.1% of clinics the advice given at any time about exercise activity is only general encouragement, and in only 16.6% did clinic staff make more specific individualised recommendations. PR is accessible in 31.3% of clinics, mainly in adult care and overall only 26.0% of clinics prescribe exercise training programmes for patients. Further details including frequency of discussion, advice given and who discusses exercise activity with the patient, and provision of exercise training programmes are available in the on-line supplemental data accompanying this article (Supplementary data C).

Table 1
Availability of equipment for exercise testing to evaluate patient health in clinics.

<table>
<thead>
<tr>
<th></th>
<th>Paediatric</th>
<th>Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Specialist centres</td>
<td>Shared care clinics</td>
</tr>
<tr>
<td>Number of clinics</td>
<td>16</td>
<td>53</td>
</tr>
<tr>
<td><strong>Equipment availability for exercise testing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pulse oximeter*</td>
<td>14 (87.5%)</td>
<td>34 (64.2%)</td>
</tr>
<tr>
<td>Treadmill</td>
<td>9 (56.3%)</td>
<td>13 (24.5%)</td>
</tr>
<tr>
<td>Cycle</td>
<td>5 (31.3%)</td>
<td>6 (11.3%)</td>
</tr>
<tr>
<td>Electrocardiogram</td>
<td>4 (25.0%)</td>
<td>12 (22.0%)</td>
</tr>
<tr>
<td>Metabolic cart</td>
<td>1 (6.3%)</td>
<td>1 (1.9%)</td>
</tr>
<tr>
<td>None of the above</td>
<td>1 (6.3%)</td>
<td>15 (28.3%)</td>
</tr>
</tbody>
</table>

* The survey specifically enquired as to whether a pulse oximeter was available for use in exercise testing beyond availability for resting oxygen saturation measurements. Two shared care clinics commented that no pulse oximeter was available in the outpatient setting at all.
The importance given by all respondents to exercise testing and training is shown in Fig. 1. Opinion from all respondents on the need for exercise testing (mean and median) was 3.5 and 4.0, respectively, and on exercise training was 4.0 and 4.0, respectively.

4. Discussion

The primary finding of this survey shows that exercise testing and training is limited or underused in the healthcare of patients with CF across the UK, despite the diagnostic and therapeutic value of exercise being recognised by healthcare providers. Similar conclusions were made from surveys investigating the use of exercise testing and training in CF centres in the different healthcare systems of the US and Germany [13,14]. Surveys in the US and Germany reported that exercise testing is performed in 43.5% and 63.0% of CF clinics, respectively. In our survey, 53.1% of clinics reported that exercise testing was used, however, the number of exercise tests performed over a 12 month period is lower (32.5%). In the US and Germany 21.7% and 15.0% offer a tailored exercise training programme, respectively, compared to 15.6% in our survey. Based on the UK CF register [15] the responding specialist centre clinics alone provide healthcare for at least 54.8% of UK patients with CF. Surveys which do not offer inducements to return the questionnaire have a response rate of ∼48.0% [16,17]. Where inducements are offered, the response rate has been found to increase to 75.0% [17], however for financial reasons inducements were not an option, as was a second mailing to clinics. Therefore, the survey response rate of 51.6% is considered a limitation and raises the possibility of selection bias in the reports returned. Non-responding clinics may use and favour exercise less and thus may therefore lead to an over-estimation in our findings of provision and the importance assigned to exercise. It is not possible to say whether this could be counter-balanced by any clinics supportive of exercise testing who were unable to respond to the questionnaire. Physiotherapists in CF teams may be more enthusiastic about exercise but were responsible for only 26.0% of the questionnaires returned, 68.8% were completed by senior medical staff.

Paediatric CF care in the UK is less centralised than adult care and it is noteworthy that the equipment for, use and scope of exercise testing is significantly greater in adult than paediatric clinics and in specialist centres than in shared care clinics. Adult respiratory care is more burdened by chronic disease limiting activity, especially COPD, for which PR services have evolved, increasing awareness, expertise and ultimately availability of services that may be accessible to the adult CF population. Measures of peak performance and training which may have a role in fitter or younger patients have limited availability. As a therapeutic intervention, training ought to be equally accessible

### Table 2

<table>
<thead>
<tr>
<th>Type of exercise tests used</th>
<th>Paediatric</th>
<th>Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Specialist centres</td>
<td>Shared care clinics</td>
</tr>
<tr>
<td>Number of clinics</td>
<td>16</td>
<td>53</td>
</tr>
<tr>
<td>6-minute walk test&lt;sup&gt;a, b, c&lt;/sup&gt;</td>
<td>4 (25.0%)</td>
<td>5 (9.4%)</td>
</tr>
<tr>
<td>12-minute walk test&lt;sup&gt;a, b, c&lt;/sup&gt;</td>
<td>0</td>
<td>1 (1.9%)</td>
</tr>
<tr>
<td>Incremental shuttle walk test&lt;sup&gt;a, b, c, f&lt;/sup&gt;</td>
<td>6 (37.5%)</td>
<td>10 (18.9%)</td>
</tr>
<tr>
<td>Endurance shuttle walk test&lt;sup&gt;a, b, c&lt;/sup&gt;</td>
<td>0</td>
<td>2 (3.8%)</td>
</tr>
<tr>
<td>Step test&lt;sup&gt;a, b, c&lt;/sup&gt;</td>
<td>8 (50.0%)</td>
<td>5 (9.4%)</td>
</tr>
<tr>
<td>Treadmill test&lt;sup&gt;d, g, h, e&lt;/sup&gt;</td>
<td>2 (12.5%)</td>
<td>6 (11.3%)</td>
</tr>
<tr>
<td>Cycle test&lt;sup&gt;d, g, h, e&lt;/sup&gt;</td>
<td>2 (12.5%)</td>
<td>1 (1.9%)</td>
</tr>
</tbody>
</table>

N.B. these are recommendations made in the literature and by the authors, it is ultimately dependent on the judgement of the supervisor as to which exercise test would be best suited to the patient.

- <sup>a</sup> Recommended for assessing exercise limitation in advanced disease.
- <sup>b</sup> Suitable for all ages.
- <sup>c</sup> Test of endurance.
- <sup>d</sup> Recommended for ages ~8 years or above.
- <sup>e</sup> Test of peak exercise performance.
- <sup>f</sup> Incremental test.
- <sup>g</sup> Typically includes the measurement of peak oxygen uptake.
- <sup>h</sup> Gives an objective measure of peak performance.

![Fig. 1. Importance assigned to exercise testing and training in the clinics (N.B. missing data represent % of respondents who did not answer this question).](image-url)
in all clinics. However, the provision of exercise testing and training is greater in specialist centres than shared care clinics. Testing was reported to be limited by resource availability in 46.9% of clinics overall. Compared to the results of our survey, CF clinics in Germany have greater availability of specialist exercise equipment [14]. Our information suggests that in the UK testing is rarely undertaken more than once a year or outside of the annual review process for patients.

This survey confirms a lack of both standardisation and provision of exercise testing and training with variability in the availability of resources between clinics. An example of variation in practice is that in two similarly sized adult specialist CF centres (∼225 patients), one centre had the availability of equipment to measure full cardiopulmonary variables during cycle ergometry exercise and had conducted 146 exercise tests in the previous year. The other centre only had equipment to measure oxygen saturation and distance during walking tests and carried out 47 exercise tests over the same period. Furthermore, in two smaller paediatric clinics (∼35 patients) one clinic conducted 34 and the other clinic only 2 exercise tests over 12 months. Both had the same equipment availability, assigned the same level of importance to exercise testing, and stated that the availability of personnel did not limit exercise testing.

The majority of UK clinics do not have the resources to measure VO$_2$peak (i.e., availability of metabolic gas analysis system with treadmill or cycle ergometer), which is the most precise method of assessing physical fitness in healthy individuals with mild disease and normal exercise tolerance, as it directly measures oxygen transportation to and utilisation by the working muscles. Walking tests, however, are more commonly used and offer a simple and inexpensive means of assessing exercise limitation. The six-minute walking test has been shown to correlate with VO$_2$peak in children with severe and moderate disease, [18,19] but, it does not accurately predict the VO$_2$peak of the patient. In early disease the correlation between exercise limitation assessed by VO$_2$peak and lung high resolution computed tomographic (HRCT) abnormalities, such as mucus plugging, is stronger than that between spirometry results, or BMI and exercise limitation [20]. Also, spirometric lung function can remain stable or improve when HRCT scores deteriorate [21] and in mild disease spirometry is not a strong predictor of VO$_2$peak [22]. Therefore, there is a greater need to direct by measure of VO$_2$peak through exercise testing.

The UK Cystic Fibrosis Trust (2001) recommended exercise testing should be performed on an annual basis, and exercise programmes should be tailored to the individual, taking into consideration disease severity, level of fitness and the patient’s preferences to exercise activities [11]. The British Thoracic Society and the Association of Chartered Physiotherapists in Respiratory Care (2009) recommends that exercise should be an integral part of CF care with training that achieves the minimum activity levels detailed in the American College of Sports Medicine guidelines [23]. Studies have reported that most children and adolescents with CF engage in physical activities at a comparable level to their healthy peers [24,25]. However, determining what is best suited to specific disease phenotypes requires further research and individuals may require a tailored regimen to ensure adherence.

In conclusion, this survey shows that UK practice falls short of recommendations due to both resource limitations and in a minority of clinics due to the opinion that exercise assessments [4 (4.2%) and training [2 (2.1%)] are unimportant. Generally, however, in the UK, like Germany, there is a discrepancy between the high importance given to the value of exercise by healthcare providers and what is available. Physical fitness and survival are strongly associated and the potential exercise training has to increase physical fitness in patients with CF means standardisation of training in clinics could improve clinical outcomes. More sophisticated objective measures of exercise performance e.g., aerobic capacity, which is not widely available, may offer a tool for monitoring disease activity and help evaluate the benefit of therapeutic interventions in early disease where lung function is not sensitive.

**Conflict of interest**

None of the authors have a conflict of interest to report.

**Funding sources**

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**Appendix A. Supplementary data**

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.jcf.2010.03.004.

**References**


