

Annual review hospital visits for patients with cystic fibrosis

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INTRODUCTION

Cystic fibrosis (CF) is a lifelong multisystem disease. All patients attend hospital on a regular basis for review and adjustment of treatment. They are treated in the clinic by a multidisciplinary team, all with a special interest and expertise in CF. The composition of the team varies somewhat, but usually comprises a doctor, a nurse, a physiotherapist and a dietitian. Other departments variously involved include the ward nursing staff, radiology/imaging, social work, psychology, psychiatry, microbiology, gastroenterology/nutrition, surgery, pharmacy and the hospital contracts department.

Little current treatment in CF is based on evidence from randomized controlled clinical trials, and many treatment regimens have been introduced into practice with no objective evaluation. Thus it is that without any controlled studies of benefit or cost, it has become the received wisdom and part of standard guidelines in the UK that all patients with CF should, in addition to regular 3-monthly hospital visits, attend for an in-depth review once a year¹. The principle of this is to enable a much more detailed proactive appraisal than is possible during the routine outpatient clinic. In most centres, including ours, this annual review visit replaces a routine 3-monthly appointment.

The immediate effect of annual review visits is to generate considerably increased activity by both patients (attending hospital, filling in diet or activity diaries) and staff, as well as consuming additional resources. The assumption is that all this additional activity is beneficial, but this has never been objectively demonstrated. Indeed, an obvious question, which has never been addressed, is why an annual review should be needed for patients who are already receiving a 3-monthly one.

Annual reviews are so well established as part of routine practice that it would now be impossible to perform a randomized controlled trial. In order to try and evaluate annual reviews, we decided to test the hypothesis that

annual review visits generate a larger number of interventions than are generated during routine outpatient clinic visits, using the number of medical, dietetic and physiotherapy interventions per attendance as the primary outcome variables.

METHODS

The data to test the hypothesis were gathered by retrospective case-note review, comparing the number of interventions arising from annual review visits with the number of interventions that arise at routine outpatient attendances. The null hypothesis was that there is no difference in the number of interventions performed as a result of an annual review and the number that were performed as the result of a routine outpatient attendance.

The study was performed in the University Department of Child Health Cystic Fibrosis Clinic at Booth Hall Children's Hospital. The clinic sees two categories of patient: those who only attend Booth Hall Children's Hospital, and those whose care is shared between Booth Hall as the regional centre and a local district general hospital.

Routine appointment procedure

All patients are seen routinely in the clinic every 3 months, or more frequently if necessary. All the core members of the multidisciplinary team (doctor, nurse specialist, physiotherapist, dietitian) are present in the same room, but individual members of the team can use a nearby room to see the patient and/or family on their own. In addition to these regular 3-monthly visits, the following items are monitored for all patients:

- . Height and weight measured at each hospital visit (routine, emergency and annual reviews)
- . Lung function tests performed at each hospital visit (routine and annual reviews)
- . Chest radiograph every 6 months
- . Ultrasound scan of liver and spleen every 24 months
- . Cough swab or sputum sent in every 2 weeks, with extra samples if unwell.

Annual review procedure

The procedure at an annual review visit, which is scheduled to last all morning, is as follows:

- Review by doctor and specialist nurse of the following items: medical history, medication and treatment adherence, sputum microbiology results, lung function tests, results of other tests (e.g. 3-day faecal fat measurements), chest radiographs and abdominal ultrasound examinations
- Separate review by CF specialist dietitian, with review of growth over the previous 12 months and calculation of the per cent body mass index for age. A 3-day diet and enzyme diary is sent to each patient with the appointment for the annual review. The completed diary is then discussed at the review, with attention to individual nutrient intake to ensure a balanced intake. Diet, enzyme intake and bowel history are discussed to highlight any problems with enzyme therapy non-compliance, and changes to enzyme dosage are made if required. If suboptimal fat absorption is suspected, a 3-day faecal fat study may be arranged before making any changes to enzyme dosage. The session is also used to disseminate any diet- or enzyme therapy-related research findings, and provide age-appropriate education to improve the efficacy of enzymes
- Separate review by the physiotherapist, which includes overview of recent clinical history, including recent courses of antibiotics, respiratory function tests; overview of current physiotherapy (demonstration of current regimen, discussion regarding understanding of current airway clearance, modification of airway clearance techniques including demonstration, frequency of treatment); overview of postal sputum samples (how often sent, type of sample); overview of current exercise, including advice on increasing/ incorporating exercise into lifestyle; overview of current medication with reference to adjuncts to physiotherapy, including timing in relation to physiotherapy, techniques and equipment used; overview of airway clearance equipment and compressors; overview of changes made; written handouts given to support verbal information and any further questions answered
- Discussion of findings with the full multidisciplinary team at the weekly meeting, always held the day after the annual review visit
- Pulse oximetry
- Assessment of number of days' school missed in last 12 months
- Self-assessment by parents, using standardized questionnaire, of how much time has been taken up in performing activities related to cystic fibrosis
- Collection of data for CF database.

All patients attending routine 3-monthly appointments or annual reviews are seen by one of two consultant medical staff.

Inclusion/exclusion criteria

Inclusion criteria were: (i) patient diagnosed with CF for more than 12 months; (ii) patient regularly attends Booth Hall Children's Hospital for all hospital treatment; and (iii) patient has had at least one annual review up to and including 17 May 2000. Exclusion criteria were: (i) patient has received shared care with another hospital; and (ii) patient has not yet had an annual review visit.

Data collection and statistical analysis

All medical, dietetic and physiotherapy interventions were categorized (Boxes 1–3). Data on interventions were obtained from the handwritten entries and typed correspondence in the medical records, and from the separately held physiotherapy and dietetic records. The number of interventions occurring at the most recent annual review visit were compared with the number occurring at the three preceding routine clinic visits. Emergency visits were not included in the study. Data on

Box 1 Categories of medical intervention

Antibiotics
<ul style="list-style-type: none"> ● New antibiotic commenced ● Dose of existing antibiotic changes ● Antibiotic formulation changed (e.g. syrup to capsule)
Inhaled drugs
<ul style="list-style-type: none"> ● New drug commenced ● Dosage change ● Change to type of inhaler (e.g. diskhaler to volumatic)
Vitamins
<ul style="list-style-type: none"> ● Dosage change ● New vitamin preparation/formulation commenced
Other drugs
<ul style="list-style-type: none"> ● New drug started ● Dosage change ● Formulation change
Investigations
<ul style="list-style-type: none"> ● Chest radiograph ● Abdominal ultrasound ● Other investigations not listed here ● Full blood count ● Coagulation investigations ● Urea and electrolytes ● Liver function tests ● Other blood tests not listed here
Other interventions
<ul style="list-style-type: none"> ● Admitted to hospital ● Referred to another consultant specialty team

Box 2 Categories of physiotherapy intervention

- Airway clearance
 - Modify existing technique
 - Introduce new technique
 - Introduce new postural drainage position
 - Advice about positioning
 - Advice about timing of physiotherapy
- Postural drainage equipment
 - Change or provide new equipment
 - Discuss possible introduction of new equipment
 - Encourage use of existing equipment
- Inhaler technique
 - Change the timing of the inhaler
 - Introduce or modify inhaler technique
 - Introduce new inhaler
- Nebulizers and compressors
 - New nebulizer
 - New compressor
 - Arrange service of compressor if needed
- Exercise
 - New type of exercise encouraged
 - Regular specific exercise (e.g. cycling) advised
 - Increase frequency of exercise
- Introduction of self-treatment
 - New techniques
 - Discussion/advice regarding airway clearance
 - Devise home programme
- Sputum sample collection
 - Change from cough swabs to sputum samples and teach patient to expectorate
 - Encourage more regular collection of samples

Box 3 Categories of dietetic intervention

- Diet
 - Changes suggested
- Supplementary nutrition
 - Diet supplement introduced
 - Diet supplement discussed (e.g. discontinued or change type/frequency)
- Pancreatic enzymes
 - Dose changed
 - How taken changed, e.g. change from emptying the capsule to swallowing intact capsule
 - When taken changed, e.g. instead of being taken before a meal capsules taken during the course of the meal
- Enteral feeding
 - Commenced
 - Discussion of possible introduction or review of treatment in progress

interventions were not normally distributed, and the Wilcoxon signed ranks test was used to compare interventions at annual review with those at routine clinics.

RESULTS

Of 87 patients with CF who regularly attend Booth Hall Children's Hospital for all their hospital care, 73 (82%) fulfilled the inclusion criteria and were studied. Because physiotherapists or dietitians were not always available at the annual review visits, all 73 patients were reviewed medically at annual review, 64 had a physiotherapy review at the annual review, and 68 had a dietetic review at the annual review visit.

The 73 patients attended a total of 208 routine outpatient clinics prior to the annual review visit; 64/73 (87.7%) patients attended the maximum of three outpatient clinics, 7/73 (9.6%) attended only two clinics, and 2/73 patients (2.7%) attended just one.

Regarding medical treatment, for a total of 73 annual reviews there were 124 interventions. From a total of 208 routine outpatient visits there were 209 medical interventions. The number of medical interventions at annual review did not differ from the number at routine clinics ($P=0.7$).

Regarding physiotherapy, for a total of 73 annual reviews there were 162 interventions. From a total of 208 routine outpatient visits there were 44 physiotherapy interventions. The number of physiotherapy interventions at annual review was significantly higher than the number at routine clinics ($P<0.01$).

Regarding dietetics, for a total of 73 annual reviews there were 44 interventions. From a total of 208 routine outpatient visits there were 48 dietetic interventions. The number of dietetic interventions at annual review was significantly higher than the number at routine clinics ($P<0.05$).

Details of the results for medical, physiotherapy and dietetic interventions are shown in Tables 1–3.

DISCUSSION

There were a number of methodological limitations to this study. In a perfect world all patients would regularly attend all appointments, and all staff would take holidays at the same time, ensuring that all patients were seen by all three main types of health professional at an annual review visit. Poor attenders may have artificially inflated the figures for interventions at routine outpatient visits, but there were only two poor attenders and this is unlikely to have unduly influenced the results. Another potentially confounding variable could have been patients who received routine interventions when attending for a sequence of emergency visits. In fact, there were only two patients who attended with more than one emergency appointment, so it is unlikely that this problem affected the overall result. A methodological issue to be considered for future studies concerns the classification of chest radiographs and

Table 1 Medical interventions—results

<i>Intervention</i>	<i>Interventions at 73 annual reviews</i>	<i>Interventions at 208 routine clinic visits</i>
New antibiotic started	8	19
Dose antibiotic changed	7	22
Antibiotic formulation changed	0	5
New inhaled drug	2	11
Inhaled drug dose change	3	5
New type inhaler	2	1
Vitamin dose change	2	1
Vitamin preparation change	6	5
Other new drug started	0	16
Other drug dose changed	2	6
Other drug formulation change	1	0
Chest radiograph	42	55
Abdominal ultrasound	39	22
Other investigations	6	16
Full blood count	0	3
Blood coagulation investigations	0	1
Urea and electrolytes	0	3
Liver function tests	0	2
Other blood tests	0	1
Admitted to hospital	1	6
Referred to another consultant	3	9

abdominal ultrasound examinations as interventions, as these investigations are performed 6- and 24-monthly, respectively, on every patient without fail, regardless of whether or not they are attending a routine clinic or an annual review. Hospital admissions are a potentially confounding variable, as staff, particularly physiotherapists and dietitians, sometimes use hospital admissions (e.g. for a chest infection) opportunistically to tackle non-urgent problems. Clearly, this could lead to interventions which were then not counted in a study such as ours. Our study did not include data on hospitalizations or the procedures that took place during hospitalization, so we cannot measure the extent to which this has been a confounder. The fact that not all patients were seen by a dietitian or physiotherapist at an annual review is explained partly by staff absences and partly by unforeseen delays during the course of the review, leading to patients missing their allotted slot with an individual member of staff. These problems could be an argument for admitting patients to hospital as a day case, though our own approach is to try to minimize admission wherever possible. Finally, the data obtained here underestimate the input from the dietitian at annual review visits, because much activity is not interventional, for example education, or improving a parent's understanding of the need for enzymes.

Table 2 Physiotherapy intervention results

<i>Intervention</i>	<i>Interventions at 73 annual reviews</i>	<i>Interventions at 208 routine clinics</i>
Modify existing airway clearance technique	32	5
Introduce new techniques	27	2
New postural drainage position	3	0
Advice about positioning during airway clearance	3	3
Advice about timing of physiotherapy	3	2
Change/provide new postural drainage equipment	10	1
Discuss possible introduction of new equipment	2	0
Encourage use of existing equipment	2	0
New nebulizer	3	6
New compressor	0	1
Service due	6	0
Change timing of inhaler	2	7
Introduce or modify inhaler technique	3	3
New inhaler	0	1
New type of exercise	3	0
Encourage more regular exercise	20	1
Increase frequency of exercise	8	1
Introduce new self treatment technique	1	0
Discuss/advice regarding airway clearance	12	1
Devise home programme for self treatment	4	0
Change from cough swab to sputum collection	9	1
Encourage more regular submission of cough swab/sputum samples	9	9
Totals	162	44

One additional confounding effect is that there are occasions when a problem is identified at a routine visit, but dealing with the problem is delayed in the knowledge that the next appointment is the annual review. This applies particularly to physiotherapy, for example if the physiotherapist identifies a need to change from percussion to the active cycle of breathing. This will tend to inflate the number of interventions at annual review visits. Finally, however much the consultant paediatrician may try to avoid it, there may well be medical domination of the routine visits. It is possible that the dietitian and physiotherapist

Table 3 Dietetic intervention results

Interventions	Interventions at 73 annual reviews	Interventions at 208 routine clinics
Diet change	8	11
Enzyme dose change	11	20
Enzymes: how taken changed	6	0
Enzymes: when taken changed	14	7
Supplementary nutrition commenced	3	8
Supplementary nutrition discussed	1	1
Enteral feeding commenced	0	0
Enteral feeding discussed	1	1
Totals	44	48

who sit in on the routine clinics may be more likely to use their initiative and adjust therapy when they have the patient to themselves at an annual review visit.

The data presented here clearly indicate that annual reviews, as practised in our centre, result in additional interventions, particularly in the areas of physiotherapy and diet/nutrition/enzyme therapy. This study, however, gives no data on whether or not this additional activity, which represents a considerable extra burden on staff, actually benefits patients. The staff all feel the activity is worthwhile, and feedback from parents also favours annual reviews.

One positive aspect of the annual review process as managed here is that it affords families the opportunity to spend time alone with individual members of the multidisciplinary team. This inevitably raises the question of whether it would be better for patients to see all professionals separately at each visit, but our own view is that this could easily result in fragmentation of patient care and reduce communication both within the team and between the team and the family. In the days when intravenous antibiotic treatment was given in hospital, these admissions provided an opportunity for an in-depth review by physiotherapy and dietetic professionals. A potential advantage of the annual review visit is that it helps to offset the lack of access to these health professionals for patients receiving home intravenous antibiotic therapy.

The difficulty of generalizing from these data is the varying way in which annual reviews are conducted. In some centres, patients receive a battery of blood tests measuring a very large number of variables. Our own policy has been to minimize invasive procedures and to try to limit

the number of investigations to those where there is the clearest evidence of direct benefit. The lack of objective evaluation of cost-benefit from annual investigations, such as measuring events of IgE, zinc and copper, vitamin E, vitamin A, liver function tests, calcium, phosphate, glucose tolerance, antipseudomonas antibodies and so on, means that there are bound to be differences of opinion about the need for all these tests.

Local circumstances are likely to be important in determining the need for, and content of, annual reviews. For example, where patients are normally seen for review by training-grade or subconsultant-grade doctors, one could make an argument for an annual review by a consultant, although one could also argue for greater consultant input between annual reviews. We have not addressed the issue of how to deal with patients seen on a shared-care basis, yet another widely used strategy that has never been objectively evaluated, and which has interestingly been largely rejected by UK adult chest physicians caring for patients with CF.

We are aware of a number of different models for annual reviews of shared-care patients, including the annual reviews being done locally by the district paediatrician, locally by the visiting regional centre multidisciplinary team, and by patients attending, or being admitted to, the regional centre. We have no views as to which approach is best, and the optimum approach is likely to vary considerably according to the skill and resources that are available in district unit and regional centres. Increasing concern about cross-infection of multiresistant organisms may affect policy, and ultimately may reduce the level of contact patients have between district unit and regional centre.

Like shared care, annual reviews were introduced by major centres in part in an effort to improve the quality of care given to patients in outlying districts. There is an impression that some of these measures have been imposed rather dogmatically. The fact is that local resources vary enormously in the UK. There is little basis on which any of these measures should be imposed either on a regional centre or on a district service, particularly given that there is no objective evidence of benefit of these strategies.

REFERENCE

1 Carr SB, Dinwiddie R. Annual review or continuous assessment? *J R Soc Med* 1996;89(Suppl. 27):3-7