



Short Communication

Annual Review Clinic improves care in children with cystic fibrosis ☆, ☆ ☆, ★, ★ ★

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Abstract

Background: It is unclear whether annual multidisciplinary reviews in cystic fibrosis (CF) patients should be conducted in dedicated annual review (AR) clinics or during continuous assessments throughout the year. Our aim was to assess the effect of introducing an AR clinic.

Methods: A retrospective written and electronic record review of CF patients was carried out for 2007 (no AR Clinic) and 2010 (established AR Clinic) calendar years. An internet-based satisfaction survey was distributed to families attending the AR clinic.

Results: In total, 123 children (mean age 9.5 years, range 1.32–18.8 years) and 141 children (8.3 years, 1.1–18.3 years) were included in 2007 and 2010 respectively. There was a significant increase in multidisciplinary reviews (documented annual review 28% vs 85%, $P < 0.001$; dietary assessment 46% vs 92%, $P < 0.001$) and investigations (OGTT 2% vs 74%, $P < 0.001$; abdominal ultrasound 35% vs 85%, $P < 0.001$) conducted after the introduction of AR clinic. The majority of the families surveyed (85%) were satisfied or very satisfied with the AR clinic.

Conclusions: CF AR clinic significantly improves the number of annual investigations and multidisciplinary reviews performed. Families were satisfied with this new process.

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Keywords: Cystic fibrosis; Parental satisfaction; Quality improvement; Delivery of care; Chronic disease management

1. Introduction

Annual reviews are embedded in routine cystic fibrosis (CF) patient care today and recommended in all international CF expert guidelines despite the lack of evidence of benefit [1–3].

Abbreviations: AR, annual review; BAL, bronchoalveolar lavage; CA, continuous assessment; CF, cystic fibrosis; CXR, chest X-ray; IgE, immunoglobulin E; NS, not significant; OGTT, oral glucose tolerance test; US, ultrasound

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An unanswered question is whether annual review is best conducted as continuous assessment throughout the year during regular quarterly visits, or as dedicated formal Annual Review (AR) Clinic visits once a year. To date, there have only been two articles written on this topic [4,5]. None of these studies formally assessed the changes before and after the introduction of a dedicated AR clinic. In UK, 63% of the specialist CF centres conduct a dedicated AR Clinic [6]. In Australia, only 19% of the CF centres have a dedicated AR clinic (own unpublished data). Less than half of the Australian centres (42.9%) are able to have each patient reviewed by the whole CF multidisciplinary team during annual reviews. At Sydney Children's Hospital (SCH), a tertiary referral and teaching hospital in Australia, a dedicated AR Clinic was established in 2008 whereby CF children attended this clinic in place of one of their usual 3-monthly appointments, as part a quality improvement initiative. The aim of this study was to

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evaluate whether the AR Clinic improved the number of annual multidisciplinary reviews and investigations completed.

2. Patients and methods

2.1. Continuous assessment procedures

Prior to 2008, each CF patient had their annual review assessment during a routine CF clinic around the time of their birthday. The CF clinic coordinator placed the annual review assessment form in the patient's file for the physician and allied health professionals to complete during the routine visit. The physician completed the necessary request forms for the annual investigations which were given to the parents. The investigations were either conducted on the day of the clinic or on another day, subject to availability. Children under 5 had their annual surveillance bronchoscopy arranged during this routine clinic assessment, and returned on another day for the procedure together with the annual blood tests under general anaesthesia.

2.2. Annual review clinic procedures

The CF AR Clinic was introduced at SCH at the end of 2008 as a quality improvement initiative because many members of the multidisciplinary CF team were not able to review all patients annually due to time constraints in a routine CF clinic. A half-day dedicated AR clinic was established in the outpatient department on a separate day from the routine CF clinic. The CF clinic coordinator coordinates the scheduling of the clinic review and the various investigations around the time of the patients' birthday. All the information and instructions regarding the clinic review, including time of radiological investigations, fasting instructions, food and enzyme diary are mailed to the family approximately 6 weeks before the scheduled AR clinic review. The child and their family spend time with each of the multidisciplinary CF team members, including a doctor, nurse, dietician, physiotherapist, and social worker/psychologist (Table 1). Children over 5 years have all the annual investigations performed on the AR clinic day. Children under 5 have their annual surveillance bronchoscopy and blood tests under anaesthesia on a separate day. Results from the preliminary investigations (such as lung function and available blood test results) and clinical status are discussed at a CF team meeting the following day. A formal annual review form is completed which includes a report from all members of the multidisciplinary team and all results of investigations. These findings are discussed with the child and family in a routine CF clinic approximately 1 month after the annual review. A typed formal annual report is given to the family and distributed to any doctor associated with the care of the patient.

2.3. Data collection

A retrospective review of written and electronic medical records of CF patients attending SCH was carried out for the 2007 (no AR Clinic) and 2010 (established AR Clinic) calendar years. The year 2010 was chosen for review as it took 2 years

Table 1
Annual review procedures.

≤5 y.o	Over 5 y.o	≥10 y.o
Multidisciplinary team review — medical, nursing, dietetics, physiotherapy, and social worker/psychologist.		
Surveillance bronchoscopy and BAL	Spirometry Complex lung function if >8 y.o. (plethysmography, lung clearance index)	
Bloods — include liver function tests, vitamin levels	Bloods — same as ≤5 y.o, with the addition of <i>Aspergillus</i> status and total IgE level	Bloods — same as >5 y.o, with the addition of OGTT
CXR	Abdominal US, CXR, bone age X-ray	Abdominal US, CXR, bone age X-ray, bone densitometry scan.

BAL — bronchoalveolar lavage.

CXR — chest X-ray.

IgE — Immunoglobulin E level.

OGTT — oral glucose tolerance test.

US — ultrasound.

to fully implement the changes. Written and electronic records were reviewed for evidence of annual investigations (including blood tests, lung function testing, and imaging studies) and multidisciplinary reviews (including medical, dietetic, and physiotherapy reviews) conducted during the 2007 and 2010 calendar years. All patients diagnosed with CF who regularly attend SCH for hospital treatment were included in this study. Children born in the year of the study were excluded as it is our clinic practise to commence annual review at approximately 12 months of age. A short informal internet-based satisfaction survey (Appendix 1) was distributed to families via email to assess their view of the dedicated AR clinic. Ethics approval was obtained from the local area health committee (HREC ref. no. LNR/12/SCHN/189).

2.4. Statistical analysis

Statistical analysis was performed using SPSS statistical software, version 20 (SPSS, Inc., Chicago, IL). Categorical variables were compared using the chi square test and presented as a percentage of response. *P*-values of <0.05 were considered to be statistically significant.

3. Results

One hundred and twenty-three children (mean age 9.5 years, range 1.32–18.8 years) were eligible for annual review by continuous assessment in 2007, and 141 children (mean age 8.3 years, range 1.1–18.3 years) were eligible in 2010 for review at the dedicated AR Clinic.

There was a significant increase in the proportion of patients who had a documented annual review assessment before and after the establishment of an AR clinic (28% vs 85%, *P* < 0.001) (Table 2). The number of annual review reports generated also increased significantly (14% vs 85%, *P* < 0.001). There was a significant increase in all the annual investigations performed

after the introduction of AR clinic, including plethysmography (15% vs 70%, $P < 0.001$) and vitamin A, D and E levels (63% vs 89%, $P < 0.001$). There was an increase in the proportion of patients screened for CF complications such as CF related diabetes through oral glucose tolerance test (OGTT) (2% vs 74%, $P < 0.001$) and osteoporosis through bone densitometry (0% vs 81%, $P < 0.001$). The number of dietetic and physiotherapy reviews also increased significantly. (Dietary assessment 46% vs 92%, $P < 0.001$; exercise test 37% vs 84%, $P < 0.001$; incontinence screen 27% vs 84%, $P < 0.001$; inhalation therapy review 21% vs 87%, $P < 0.001$).

Of the 141 patients from 131 different families included in the study from 2010, 110 families (84%) were contacted through email to complete the satisfaction survey. Fifty-one families (46%) responded. Overall, 85% of the respondents were satisfied (34%) or very satisfied (51%) with the annual review process. Only one person (2%) was very dissatisfied with the process, 13% were neutral. Just over half of the families (51%) felt the duration of the clinic was just right, 19% felt it was too long, and 6% felt it was too short. Most families (83%) felt the AR report generated was helpful, 15% were neutral, 2% felt it was unhelpful. In particular, 44 out of 51 (94%) families felt that the AR report helped in the management of their child's CF, and that the report helped expand the parents' (85%) and their children's (56%) knowledge of CF.

4. Discussions

Our study demonstrates, for the first time, that the AR clinic significantly increases the number of annual multidisciplinary assessment and investigations compared to continuous assessments.

Previously, Carr and Dinwiddie [5] described the annual review process and investigation results from 100 children who underwent formal annual reviews. They also reviewed 20 patients who did not have annual reviews and found that although most had spirometry and chest X-ray performed annually, blood tests were only done in a minority. Hence they suggested that a formal annual review would allow the CF team to recognise medical problems such as liver dysfunction and abnormal blood glucose earlier due to the implementation of regular blood tests in the annual review process [5]. Long et al demonstrated annual reviews result in more interventions particularly in the area of physiotherapy and dietetics compared to routine outpatient visits in the same patients, which is not surprising as the number of interventions arising from routine visits depends on clinical grounds [4]. Neither study formally assessed the changes to the annual review process by having a dedicated AR clinic compared to continuous assessment.

A major limitation of this study is that we did not assess for, and hence cannot demonstrate, improvement in clinical outcomes as a result of the increased investigations and reviews afforded by the dedicated AR clinic. Previous studies have indicated the potential benefits of annual investigations. In a study involving preschool CF children, 11% had management changes as a result of abnormalities identified from their annual blood tests [7]. Further, our centre previously demonstrated that routine oral glucose tolerance testing in CF children resulted in early treatment with insulin and subsequent improvement in lung function and nutritional status [8,9]. Only through continuous prospective transparent benchmarking and ongoing clinic data analysis are we likely to be able to assess the impact of the AR clinic on clinical outcomes; this approach forms the basis of the quality improvement initiative supported by the Cystic Fibrosis Foundation in the USA.

An overwhelming majority of the families surveyed were satisfied or very satisfied with the annual review clinic. One limitation of the study is the use of a non-validated questionnaire to assess the families' satisfaction with the clinic or changes in their knowledge of CF. However, it is recognised that data collected using non-validated site-specific satisfaction surveys can be helpful in assessing clinical practise [10]. Although the use of an internet based survey instrument allowed patient anonymity and ease of data collection, it did limit the respondents to only those families who had internet access.

Another limitation of the study is the retrospective nature of the analysis. Our data analysis was dependent on identifying annual reviews and investigations from patient records. Therefore, it is possible, particularly in our 2007 data, that an annual review was carried out but not formally documented in written records, leading to a falsely low number of reviews in 2007. However, because we obtained the blood and radiology investigations from electronic records (and double checked from paper records), we believe that the increase is a real

Table 2
Annual review capture rates before and after commencement of Annual Review Clinic.

Annual review or investigation performed	2007		2010		P value
	Performed/eligible	%	Performed/eligible	%	
Documented annual review	34/123	28	120/141	85	<0.001
Annual review report	17/123	14	120/141	85	<0.001
Plethysmography (>8 y.o)	10/68	15	49/70	70	<0.001
Vitamin A, D, E levels	78/123	63	125/141	89	<0.001
Liver function tests	92/123	75	127/139	91	<0.001
Prothrombin time (>5 y.o)	14/94	15	76/96	79	<0.001
Total IgE	58/123	47	126/139	91	<0.001
Aspergillus screen (>5 y.o)	7/94	7	77/96	80	<0.001
OGTT (≥ 10 y.o)	1/56	2	34/46	74	<0.001
Surveillance BAL (≤ 5 y.o)	19/29	65	41/45	91	0.01
CXR/Chest CT	53/123	43	119/141	84	<0.001
Abdominal US (>5 y.o)	33/94	35	80/96	83	<0.001
Bone densitometry (≥ 10 y.o)	0/57	0	34/42	81	<0.001
Dietary assessment (qualitative or quantitative)	57/123	46	130/141	92	<0.001
Exercise test (>6 yrs)	31/82	37	70/83	84	<0.001
Inhalation therapy review	19/90	21	99/114	87	<0.001
Musculoskeletal exam (>8 yr)	14/68	21	58/70	83	<0.001
Incontinence screen (≥ 10 yr)	9/33	27	21/25	84	<0.001

IgE — immunoglobulin E.

OGTT — oral glucose tolerance test.

BAL — bronchoalveolar lavage.

CXR — chest X-ray.

US — ultrasound.

NS — not significant.

effect following the introduction of the dedicated annual review clinic.

5. Conclusion

The introduction of a dedicated AR clinic significantly increased the number of annual investigations and multidisciplinary reviews compared to continuous assessment in children with CF. It has been well received and is appreciated by the families we care for. Further data and continual surveillance are required to determine if the dedicated AR clinic leads to improved clinical outcomes in CF children.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <http://dx.doi.org/10.1016/j.jcf.2013.09.001>.

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