227 Detecting early markers of CF-related pulmonary exacerbations using home telemetry and sputum biomarkers

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Objectives: Acute pulmonary exacerbations (APE) are the greatest cause of morbidity in patients with cystic fibrosis (CF). Home based detection and monitoring of APE might ensure prompt initiation of therapy and rapid switching of ineffective antibiotic regimens that could potentially result in reduced hospital clinic appointments and admission and better long-term lung health. We therefore sought to assess whether daily home monitoring of sputum bacterial biomarkers and clinical parameters might provide advanced warning of infective exacerbations and/or treatment failure.

Methods: On a daily basis for a 6 month period, 15 adults with CF were asked to collect sputum samples, undertake home-based telemetric physiological monitoring (of FEV1, PEF, heart rate, saturations, weight, activity) and complete wellness and cough diaries. Sputum samples were retrospectively analyzed for levels of *Pseudomonas* exotoxin A (PEA) levels and complete data sets were examined to evaluate which parameters best predicted APE.

Results: Patient compliance with home monitoring was excellent. A number of combinations of physiological parameters may allow early, pre-symptomatic detection of APE. In a subgroup of patients, relative changes in PEA may also predict APE.

Conclusion: Home monitoring was acceptable to patients, provided unprecedented temporal resolution of clinical parameters and allowed analysis of sputum biomarker changes preceding an APE and during antibiotic therapy. PEA may prove an effective biomarker, when combined with other parameters, for early detection of APEs and treatment failure in patients with CF.

228 Telemedicine videoconferencing − breaking down the barriers for cystic fibrosis (CF) patients living in rural and remote areas

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Objectives: To use telemedicine to improve access to care for CF patients in rural settings. We examined 40 patients who have commenced clinic review using telemedicine videoconferencing (TMVC). Patients living in rural areas were targeted for participation.

Methods: The TMVC cohort was compared to the non-TMVC CF population at our institution. A standardised remote area classification grading system (Australian Standard Geographical Classification) was used to determine remoteness, classified as R1: Major Cities, R2: Inner Cities, R3: Outer Regional and R4/5: Remote/Very Remote. The Socio-Economic Indexes for Areas (SEIFA) data from the 2011 national census was examined to determine degree of advantage/disadvantage (mean national value 1000).

Results: 73% of patients receiving TMVC lived >100 km from specialist centre (mean 197, SD 151), compared to 23% for the general CF population (mean 75km, SD 151). 15% of TMVC patients were from R3, compared to 4% for the comparison group. Mean Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD), and Index of Education and Occupation (IEO) were significantly lower for the TMVC patients than the general CF population; 966 versus 1017 (p < 0.001), and 968 versus 1037 (p ⩽ 0.001), indicating greater socioeconomic disadvantage.

Conclusion: TMVC represents an additional means of outpatient assessment and review. Our institution utilised this technology primarily for patients from rural and remote areas as an alternative means of medical and allied health assessment. Access to healthcare for a group of patients from socially disadvantaged areas has been improved by facilitating specialised outreach using TMVC.

229 Review of personal hand held record for cystic fibrosis children

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Background: There is no standardized patient held records for Cystic Fibrosis (CF) patients in the United Kingdom. After an extensive consultation process with CF children and families, a Personal Hand Held Record (PHHR) was created. The PHHR has eight sections that include personal data, allergies, medicine lists, growth chart, lung function tests, physiotherapy, blood and microbiology results.

Objectives: To ascertain the usefulness of a personal record for patients with Cystic Fibrosis and their families.

Methods: Young adults and parents were interviewed regarding the usefulness of a PHHR. A national feedback was also sought online at Cystic Fibrosis Trust website. There was an universal positivity towards the need of such record. Once the PHHR was created and rolled on for 1 year, a feedback survey was created. A 15 question survey was created for CF families to fill and return anonymously.

Results: 82 Patients were sent the survey. 30 patients have returned the survey to date. 24/30 (80%) found it as extremely useful or useful. Parents whose children were newly diagnosed children with CF were more likely to use it as they felt the need of writing down several informations in one place. 24/30 (80%) used it regularly for the clinic appointments, while 10/30 (33%) used it for holidays as a useful source of information for emergencies. Comments included: 'it is a Godsend' 'this is my memory!'.

Conclusion: A concept of PHHR for any chronic disease is very useful. It gives the children and parents control of their disease and provides a single point for recording data and storing documents. This is especially useful when going away or visiting health care professionals.

230 The development of a new quick/easy CF wellness score (Alfred Wellness Score for CF, "AweScore-CF") to improve delivery of clinical care in the outpatient and inpatient settings suggests patients acclimatise to low lung function

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A need for a quick/easy wellness scoring tool for use in a large adult CF unit to improve delivery of care was identified.

Objectives: To develop a short and simple questionnaire including aspects of daily life that encompass wellness for routine use across the adult CF population during baseline state and acute exacerbations.

Methods: With Alfred Ethics Committee approval a 10 item wellness score was developed using a 1–10 point visual analogue scale (VAS) by members of the CF multidisciplinary team (MDT). The anchors of the VAS were 1 = least well; 10 = most well. Perfect wellness = 100%. The 10 items were: amount of coughing in 24 hours; sputum volume; energy levels; exercise participation; appetite; weight; mood; anxiety; sleep amount/quality; and general health.

Results: A total of 145 patients (70 male) participated, 102 during baseline function vs 43 during acute exacerbations requiring IV antibiotics. Mean (standard deviation) and range: age 31.4 (10.2) [19−71] vs 33 (10.3) [21−49] years. FEV1%pred 63.3 (23.1) [22−114] vs 51.1 (19.3) [21−101]. Patients enthusiastically completed the score in 1−2 minutes. During baseline state those with mild to moderate lung disease (FEV1 >40%) had mean score 72.4 (13.0) vs those with severe disease (FEV1 <40%) score of 64.5 (11.4), p = 0.093 ns. The score quickly highlights problems that require treatment from the MDT and may assist in deciding when to start and stop therapies.

Conclusion: This well accepted quick/easy tool may improve delivery of care to CF in the outpatient and inpatient settings. Using this score we conclude that patients acclimatise to low levels of lung function in advanced disease with reports of relatively high levels of perceived wellness.