Development of a secure, on-line clinical health record to improve care in cystic fibrosis (CF)

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Background: Research into the influences on the natural history of CF continues. This has translated into clinical advances in cystic fibrosis care that have significantly increased survival over the past 40 years. Recently, there has been an increased focus on using information technology. AIM: To develop a secure, electronic health record for use in CF care (CFeHR).

Method: A consultation process, including pre-implementation surveys, occurred. An existing chronic illness application was modified for CF. Hospital systems were linked to the eHR to capture information required for complex, multi-disciplinary management.

Results: Survey responders were positive about the proposed CFeHR. Staff spent in excess of 30 mins/day seeking information in the paper-based record. The CFeHR is easily navigated. Multiple clinicians can access real-time results and care plans across settings. Security is via individual certificates issued by Medicare Australia. The application uses HL7 messaging to integrate with hospital systems and interface with the national CF data registry for reporting. Remote consultations via personal computer video-conferencing with lung function monitoring are also possible. Change management strategies have also been developed.

Conclusion: Successful implementation of the CFeHR required stakeholder input, cooperation with Information Technology personnel and situation-specific change management strategies. Supported by: The Victorian Cystic Fibrosis Clinical Information Management Program is funded by a Managed Health Network Grant from the Dept of Health and Aging. This program has met the requirements of the Bayside Health Ethics Committee.

Estimating renal function in paediatric cystic fibrosis patients

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Introduction: Acute renal failure is increasingly recognised in cystic fibrosis patients. It is believed to be related to aminoglycoside use. It is not known how many cystic fibrosis patients have underlying impaired renal function, or the best way of assessing this.

Aims: To survey the renal function of a cohort of cystic fibrosis patients using different formulas for estimating the glomerular filtration rate.

Methods: The estimated glomerular filtration rate (eGFR) was calculated for 109 (56 male) cystic fibrosis patients aged 1 to 15 years old who received care at Sheffield Children’s Hospital. Four of the most well used calculations for eGFR (Modified Diet in Renal Disease (MDRD), Cockcroft and Gault, Schwartz and Counahan) were performed.

Results: 38 patients had mildly reduced GFR and 13 patients moderately reduced GFR with the Cockcroft and Gault calculation. Eight had mild kidney disease with the Counahan formula. All had normal renal function with MDRD and Schwartz calculations. On further analysis of the eight patients with mild renal failure according to the Counahan formula, 3 had further risk factors for having impaired renal function e.g. PDA ligation, multicystic kidney disease, frequent courses of tobramycin. These patients will receive further evaluation with a formal estimate of creatinine clearance.

Conclusion: None of the cystic fibrosis patients in this study were identified as having severe renal failure with the calculations used. However the variability of estimated GFR formulas suggests they are unlikely to be a reliable indicator of renal function in paediatric cystic fibrosis patients. Those patients who have frequent courses of aminoglycosides or other risk factors for renal dysfunction will require close scrutiny. Further prospective evaluation is required.

Impact of allergic sensitization on CF-associated chronic rhinosinusitis – Results from a multicentre interdisciplinary study

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Introduction: On the one hand chronic rhinosinusitis (CRS) is a hallmark of CF, as the CFTF-defect equally involves upper airway mucosa. On the other hand allergic rhinosinusitis is the most frequent chronic disease in the general population. The aim of our study therefore was to evaluate the role of allergy in CF-associated CRS. The aim of our study therefore was to evaluate the role of allergy in CF-associated CRS. Methods: 145 CF-patients from 5 German centres were assessed for allergic sensitization by total and specific serum IgE and for CRS-symptoms with the Sinus-Nasal-Outcome-Test-20 (SNOT-20) as specific score for CRS-related quality of life. Rhinoscopy was performed, and anti-allergic medication was quoted.

Results: 63/145 CF-patients report allergy symptoms but only 42 (67%) resulted positive in allergy testing. 46/145 patients (32%) suffered from CRS according to EPOS 2007 criteria and 49 (34%) had acute intermittent symptoms (<12 weeks a year). 50 (34%) did not fulfil the EPOS criteria but 15 of them reported on remittent or chronic nasal discharge. Of the 46 patients with CRS, 20 (43%) showed allergic sensitization with specific IgE of at least CAP-class 2 (~0.70kU/l).

Discussion: About 1/3 of CF-patients suffers from chronic and 1/3 from remittent rhinosinusitis. The proportion which estimates to be allergic is considerably higher than the proportion of patients with proven sensitization. This shows that the role of CF-related chronic rhinosinusitis in CF itself is relevantly underestimated.