Implementation, uptake and impact of a cystic fibrosis electronic patient record system

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In 2007, we introduced a cystic fibrosis (CF) electronic patient record (EPR) system (modified EMIS PCS). We report the results of a staff survey investigating implementation, uptake and impact of EPR on clinical work and delivery of care. The survey was based on a modified questionnaire by Laerum et al., (2004) with sections covering computer experience, access to hardware, reliability of software, assessment and satisfaction of all aspects of EPR and perceived impact on the unit's performance.

A total of 27 members of the multidisciplinary team responded (8 doctors, 4 nurses, 2 health care assistants, 3 dietitians, 4 secretaries, 5 physiotherapists and a pharmacist). Despite 18 staff having no prior experience with EPR, nobody wished to return to paper records. Most felt that the unit could and should move away from paper records as duplication was one of the commonest complaints. Success of EPR was rated as excellent, good and fair by 12, 13 and 2 people respectively. Over 50% felt that EPR had improved the quality of work. Areas where performance had been made significantly easier included, automatic letter generation, ease of accessing information and graphical representation of serial measurements. Importantly >90% of clinical staff felt that the system helped identify clinical deterioration sooner with 100% of all responders reporting improved communication between the MDT.

EPR has been successfully integrated into our unit, with members of the MDT reporting significant benefits. EPR was felt to be a very positive move forward and has the potential to improve both the quality and the effectiveness of care. Results of this survey will have direct impact on improving the next generation of EPR due to be launched later in 2009.

Anatomopathological changes in dead children with cystic fibrosis

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Aim: To study the most common changes of the internal organs and the most frequent complications that caused the death of the children with cystic fibrosis (CF).

Material and methods: This study includes a retrospective review of the dead CF children medical documents for 12 years (from 1995 till present).

Results: In this time age had died 31 children and on the autopsy was confirmed CF. The lifetime CF diagnosis based on compatible clinical and laboratory findings in 12 children (38.7%) was established. Eight children (25.8%) had complicated meconium ileus that caused the death in newborn period. A definitive final diagnosis could not be recognized in 11 cases (35.5%) with severe lung infection and septicemia. Most of children (87.1%) has died during the first year of the life, 2 children lived till 2–3 years, 1 child – 12 years and 1 child – 17.5 years. The anatomopathological diagnostic of CF in all this children was established by macroscopic and histopathologic examinie which revealed the characteristic changes. The dominant pathological changes were finding in pancreas and were present in all children died of CF. Anatomopathological examination of the pancreas revealed fibrosis and atrophy of the pancreatic tissue and cystic dilatation of glands ducts. Pulmonary infection (bronchitis, pneumonia) were discovered in 90.3% cases. Hepatic steatosis was a common finding during anatomopathological examines (4 cases). Pathological changes in CF have progressed with the degree of malnutrition in deceased children.

Conclusion: The most common anatomopathological changes in CF children were found in the respiratory system and pancreas, by implication of exocrine glands ducts. Death occurred by meconium ileus in neonates, or by developing infectious complications in older children.

New method for charting pulmonary function history

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Three year periods of PFT results are used by CF centers to review the recent clinical course of patients' lung disease. As the life expectancy of CF patients increases, the history is ignored as attention focused on recent events. Ignoring the lifelong PFT history reduces the possibility of identifying changes in treatment or other factors that are still active and may need new treatment. We suggest a graphing technique for presenting lifelong PFT data.

All PFT results were used to generate the chart of percent predicted FEV1 and FVC for CF patients. Since recently most of CF patients start the PFT around age three, mixed prediction equations covering age 3 to 80 were used to calculate composite percent predicted values of FEV1 and FVC. The overview graph displayed upper right hand corner of the main graph shows age up to 80. The hospitalization, showing greater drop of FEV1 generally, is displayed as a vertical bar at the bottom of the abscissa. We used calendar year with age on the abscissa.

The chart could show

– Treatment Effect during Hospitalization: The FEV1 can be compared between before and after hospitalization.
– Identification of PFT pattern: It is possible that the change of FEV1 is caused by whether the long or short term effect from the trend of FEV1.
– In the abscissa, the calendar year and age are displayed simultaneously. It is helpful to understand external factors such as new treatment and environmental change.

This charting technique is designed to raise questions about the clinical courses and treatments by patients, parents, as well as, physicians, respiratory therapists, nurses, and social workers. The questions that we hope will be asked related to medicines, season, changes in the families, changes in the treatments to increase the collaboration will guide them for the treatments of acquired health problems.

Outreach clinics for the provision of specialist cystic fibrosis (CF) care to remote areas

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Background: Specialist care in a regional Centre improves outcome for patients with CF. Access to a Centre is difficult for patients in remote areas. Cumbria does not have adult CF services, patients travel to Newcastle. We established an outreach clinic whereby the CF team travels to Cumbria. The service was evaluated by patients and the team.

18 (8.7%; mean age 25.4 (18−67) yrs) of 208 patients attend the outreach clinic. 14 have Pseudomonas infection. Mean FEV1 is 2.65 L (74%) (1.44 L (44%–4.19 L (108%)); mean BMI is 20.7 (16.4−25.1). Patients are happy with outreach care: 9 (50%) prefer this setting, 7 (39%) like some care in outreach and some in the Centre, 1 (5%) prefers all care at the CF Centre, and 1 (5%) is unsure. All are happy to attend the CF Centre when needed. Outreach clinics reduce mean traveling distance from 86 to 27 miles and travelling time by a mean of 131 mins. No specific problems were identified with outreach care. For the 7 members of the CF team, outreach clinics involve extra preparatory work (range 0–4.5 hrs) and travel time (3 hrs). Although full clinical assessment and IV antibiotics are undertaken in the outreach clinic, facilities are considered less good. Flexibility in scheduling visits and segregation of patients are difficult. All recognize outreach as helpful for patients in providing care closer to home.

Conclusions: Outreach care is popular with patients and allows some care to be delivered closer to home by the CF team. The team is keen to provide this service but recognize constraints on what can be done in an outreach clinic. Patients need access to the CF Centre for inpatient care, annual reviews and complex procedures. Outreach care involves more work and time for the CF Team.