305 Comparison of contacts to adult and paediatric cystic fibrosis Clinical Nurse Specialists

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Introduction: Clinical Nurse Specialists (CNS's) are commonly the primary point of contact in cystic fibrosis (CF) centres.
Aim: To identify and compare preferred modes of contact to paediatric (P) and adult (A) CF CNS's for healthcare users. To identify when patients take responsibility for their own management.
Method: P and A CF CNS's prospectively recorded how, why and by whom they were contacted over a 30 day calendar month. CNS's were available via telephone and email. The P team have a pager for messaging, A CNS's have a mobile telephone.
Results: 340 contacts were received (130 P, 210 A) from clinics of 130 P and 147 A patients. Contact methods: phone 57% P vs 75% A, email 12% P vs 7% A. Pager 31% P vs mobile texts 18% A. No children initiated contact in the P clinic. 2/12 patients <18 years in the A clinic initiated contact. All contacts were from the patients after the age of 18 years. 12 contacts to the P CNS were from Health Care Professionals (e.g. GP, community nurse). Reasons for contact: Respiratory management 42% P vs 39% A. 30% of the A contacts were for administrative issues, e.g. outpatient appointments or admission dates, vs 6% in P. Referral on to other team members was necessary in 12% P vs 21% A.
Conclusions: Patients <18 yrs rarely take responsibility for their own management by contacting their CF CNS, leaving this to parents. Email contact was lower than anticipated in both P and A centres. There was a higher per capita rate of contact from the adult patients 1.4 vs 1, as well as a higher need for further MDT involvement, possibly reflecting their increasing medical needs. This age group utilise technology to contact their CNS's less than expected.

306 An audit of the clinical pathway of transition of young people with cystic fibrosis to adult care

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We have been running a cystic fibrosis (CF) transition clinic since 2007, after a local survey established the need for a transitional care pathway for young people with CF between our paediatric and adult centres.
Objective: Our aim was to establish the effectiveness of our current CF transiitional care pathway.
Methods: The audit took the form of a patient questionnaire. Participants were aged between 17 and 22 years, had to have attended the transition clinic and still be in attendance at the local adult centre to be eligible.
The questionnaire was hand delivered to all eligible patients either at clinic or during a hospital admission over a 3 month period. The questionnaire was constructed of both open and closed questions and included a number of 'free text' sections. We incorporated the use of a Likert scale for two of the questions which focussed specifically on individual knowledge of disease and ability to manage day-to-day care.
Conclusion: Overall there was a 59% response rate. All young people transferred to adult care by their eighteenth birthday, all transfer dates planned in advance and all but two respondents felt they were 'ready to transfer' at the time they did.
Using a Likert scale showed a significant difference in the knowledge base of individuals compared to the confidence they felt in managing their daily care.
The audit also highlighted to us that the provision of information young people received about their disease was unsatisfactory and that improvements in educational material would overall enhance the transitional care we provide.

307 Safety of PICCs in children and adults with cystic fibrosis

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Background: Peripherally inserted central catheters (PICC) are frequently used in patients with cystic fibrosis (CF) for iv antibiotic treatment. Many patients prefer repeated PICC insertion instead of a total implantable venous access device (TIVAD).
Method: The use of PICC in our CF population (n = 287) was evaluated retrospectively from February 2006 until October 2011. Events registered included: frequency of PICC insertions; number of catheter days; problems reported by patients, ward nurses and homecare team; number and type of interventions.
Results: During the study period 234 PICC have been inserted in 62 patients (169 PICC in 39 adults [2385 days] and 65 PICCs in 23 children [1035 days]). Mean (min–max) catheter dwell time was 14 days (4–31 days in children; 2–56 days in adults).
In children insertions were done under general anesthesia (13) or under an analgesic gas (18) (meopa). In all other cases a local anesthetic was used.
Minor problems were reported:
1. vascular access problems occurred in 11 (4.7%)
2. catheter loss due to accidental removal in 3 (1.3%), curled catheter (1) or catheter leakage (2)
3. catheter obstruction in 13 (5.6%)
4. insertion site related problems in 13 (5.6%)
5. general side effects in 2 (0.9%)

Three of the 7 events involving vein stenosis occurred in patients who had ⩾4 PICCs inserted at the same side in 1 year.
Discussion: PICCs can be used safely in patients with CF who require iv antibiotic treatment. Serious complications are rare, minor problems may occur, especially in patients with repeated PICC insertion. Additional data are needed to assess the safety of repetitive PICC insertion and the need for vascular imaging before insertion.

308 Assessing medication adherence in adult CF patients: involvement of the community

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Background: Adherence to treatment, especially prescribed medication, is essential for good CF care. In the UK, although CF patients are cared for in specialist centres most of their therapies are prescribed and dispensed in primary care, making adherence assessment problematic. We wished to study this further.
Method: We looked at primary care medication and dispensing lists and compared them with hospital records in 51 adult CF patients attending the annual screen clinic.
Results: The primary care medication list was concordant with clinic records in only 37 cases (72.5%). Regular monthly medication collections occurred in 29 cases (57%); a further 11 patients (21%) collected medications selectively and 2 patients (4%) did not collect any. In 9 patients (17%) the general practitioner was unable to provide data regarding the medicines being issued. As regards adherence, it was judged good in 55%, moderate in 11%, and poor in 9%.
Conclusions: The use of primary care medication lists facilitates the judgement of adherence to therapy in CF. A small proportion of CF patients appear to have poor medication adherence, and it is of concern that there was poor concordance between hospital and primary care lists in a quarter of cases. The employment of a specialised CF pharmacist may aid this.