

331 A survey of transition to the adult cystic fibrosis (CF) Centre at Papworth Hospital

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Formal guidelines have been established in the UK for transition to adult care. The Papworth Hospital CF team perform yearly transition clinics at each referring hospital. We wished to establish whether young people with CF were satisfied with our transition arrangements.

18 questionnaires were sent out to individuals who had transferred to the CF Adult service at Papworth Hospital in the last 12 months. The questionnaire was a combination of closed and free text questions, which were focused around age of transition, factors affecting the choice of adult clinic and whether individual's expectations of transition have been met.

Twelve questionnaires (67%) were returned. 8 people (67%) attended a transition clinic at their paediatric referring hospital in order to meet the adult CF team prior to transition. Five of these (62%) thought this was useful. Of the 12 respondents, 8 (67%) met the adult team between the ages of 14 and 16 and 4 (33%) met the team after they were 16. Nine individuals (75%) stated age 14–16 as their preferred time to meet the adult team. No-one felt the need to meet the team below the age of 14. Eleven (92%) of people had been offered a visit to Papworth Hospital prior to transfer. Six attended and all found it useful.

The most important factor in determining the choice of adult centre was proximity to home, followed by the reputation of the hospital and the success of the informal visit. All respondents were either very satisfied or satisfied that their move to adult services had met their expectations.

This survey confirms the success of a transition process which follows UK CF Trust guidelines.

333 Basic structure of daily programme for patients with cystic fibrosis

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Cystic fibrosis – a genetically caused disease – requires everyday challenging care of affected children. Quality of this care and quality of survival of CF patients depends on several factors. One of these factors – which appears to have a priority in the community care – is an individual structured daily programme.

Aim of the authors was to arrange a basic structure of the diurnal programme based on the experience gained during a two-year follow-up of basic as well as specific needs of CF children aged from 6 to 15 years. Basic data were obtained by a combination of review and observation methods. The final structure of diurnal programme was designed after careful analysis and synthesis of data. The theoretical/practical requirements of individual members of CF team were also considered.

The authors consider the proposed structure of diurnal programme as a significant aid for the design of an individual diurnal programme for each child within the community-based care. Purpose of this structure is to help the child with CF to eliminate basic selfcare-related problems.

332* How to improve the daily management of implantable catheter ports (ICP)? Proposal of a practical tool for nurses and physicians

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Background: In Cochin CF centre 70% of CF patients have ICP. Complications are frequent (42%) especially occlusion (21%).

Aims and Methods: A multidisciplinary group (nurses, head-nurses, physicians, chemists, anaesthetists, surgeons, hygienists, media workers, medical devices manufacturers) works to improve ICP management. Effective, safe and ergonomic cares, patient safety and comfort and economic restraints were omnipresent topics during discussions. Differences in medical and nursing practices, cultural habits in hospital prescriptions, absence of national medical consensus were observed.

Results: The working group draw up a poster displayed in the nurse office. This practical tool with photos and diagrams described ICP handlings, maintenance between uses, procedures in case of complications. Impact of the poster on nurse ICP knowledge was evaluated before and 4 months after display. Knowledge improvement and a decrease of ICP complications was observed.

Interested by this tool, 6 medical teams from different hospitals, including the 3 most important ICP implanters joined the initial working group. In that way poster content evolved since October 2004 and was ratified by the different infection control committees in January 2007.

Conclusion: The poster will be displayed in the major public hospitals in 2007. The final issue will be presented to you in the poster session.

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334 Use of central venous catheters in people with cystic fibrosis in Italy

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Patients with CF have to undergo frequent IV antibiotic treatment but with passing of time it becomes increasingly difficult to find a suitable peripheral venous access. The insertion of Central Venous Catheters (CVC) has become frequent in patients with CF. In Italy, data are lacking about the frequency of CVC use in CF patients and no guidelines exist on the use of CVCs in patients with CF.

Goals: To estimate the prevalence of CF patients with a CVC in Italy.

A 17-item questionnaire was sent to all Italian CF Centres. 19 CF Centres, following a total of 2256 patients (55% of all Italian CF patients), answered the questionnaire. 54 patients (2.4%) have a CVC. Of these, 1.8% of patients are under age of 2, 3.7% are aged 3–6, none is aged 7–13, 25.9% patients are aged 14–18 and 68.5% are adults. At the moment of survey 55 patients were under consideration for implantation of a CVC. Among the patients with a CVC, 96.3% have a Port and 3.7% have a tunnelled CVC. 27 cases of CVC removal have been reported, reasons were: obstruction (11.1%), dislocation (14.8%), infection (22%), rupture (18.5%). In 25.9% of cases the CVC was removed because it was no longer necessary (e.g. after a transplantation).

7 Centres (equal to 612 patients) do not have any patient with a CVC. In 4 Centres (570 patients) more than 5% of the patients have a CVC. The percentage of patients with a CVC in all Centres varies from 8.6% to zero.

The most frequent reasons for the implantation of a CVC were: lack of superficial venous accesses (64.5%), need to carry out home therapy (15.5%), infusion of hypertonic or irritant medications (11.8%), frequent hospitalisation (5.5%).

This study highlights the need of guidelines providing indications about CVC insertion in CF people.