289 Group work as a coping skill for children with CF, ages 9–12

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For children with CF the requirement to adhere to intense therapy may impair their lifestyle and interaction with their peers.
Our multidisciplinary team explored techniques to transfer the responsibility for the care from the parent to the child, thereby giving the child the tools to navigate the social, familial and medical surroundings. Adherence to therapies therefore will originate from the child and not by coercion from the outside.
Child friendly support groups integrating art, written expression and craft allow an individualized, nonverbal mode of communication. The children share and offer support and advice, the team communicates the message to the children that they continue to help building a trusting and secure relationship between staff and patient.
Methods: Girls, 9–12 y, 7 meetings, 90 min. (intro. 10 minutes, activity 30–45 min., discussion/conclusion 25–30 min.), clinic days, hygienic measures. Specific topics: responsibility, confidentiality, clinic visits, my daily schedule, my identity/name, coping strategies.
The group work helped the children to integrate the intensive daily therapeutic regiment into their everyday normative lifestyle. The facilitators acquainted themselves with the patients on an intensive level, evaluating and monitoring their individualized needs. The staff was counseled on how to deal with the individual personality of the child. The group offered the opportunity to share feelings, cope with strategies and enhanced the confidence/self-esteem of the children. The participants reported their satisfaction and anticipation for continued similar experiences. No cross infection of pseudomonas occurred.
Support groups can act as a powerful therapeutic setting for children with CF to enhance the self-image. Support groups can be created while adhering to hygienic regulations.

290 Diagnosis – how does it feel?

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Introduction: Parental recall of the process of diagnosis is still fresh up to 15 years after the event. As part of a small service related project 4 years ago a retrospective semi-structured questionnaire was administered to 20 parents of CF children related to their experience of diagnosis. This information has been reproduced in leaflet form as a potential resource for parents at diagnosis.
Aim: To gain parental feedback on a leaflet about experience of diagnosis of CF as part of evaluation of standard practice and to use parent advocacy to inform good clinical practice at diagnosis.
Method: The leaflet was given to parents for feedback. Some parents had recently been given the diagnosis of CF within the last year other parents had children who had been diagnosed between 5–10 years ago. Feedback was sought regarding how helpful would the leaflet have been at the time of diagnosis? What should or could be changed to make the leaflet more effective? Feedback was also sought regarding its potential usefulness as a resource for health professionals to aid their understanding of parents' experiences. Written feedback will be summarised and grouped into themes as to how parents felt the leaflet could be improved or any reservations they had about its use.
Results: We are awaiting responses from parents who have been given the leaflet.
Discussion: At the time of diagnosis, parents are given a great deal of practical information when they are trying to process very complex emotions. There is a lot of good educational information about the illness but little about the impact on parents receiving the diagnosis from an emotional viewpoint. We hope that this leaflet will be seen as a positive addition to our standard practice and that it begins to help parents deal with the lifelong process of accepting a diagnosis of CF.

291* Nutrition education program in cystic fibrosis children

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Adequate nutritional status is one of the main factor for long-term survival and well being in CF children. Nutritional education is provided to the parents at the time of diagnosis to ensure that the patients achieve optimum nutrition therapy. However, little is done for the children themselves.
We conducted an observational study in our cohort of CF children and observed that most of them had no or little knowledge about nutritional aspects of their disease, correct use of enzymes, and interest of high-energy food.
We therefore undertook an educational program in 13 children aged between 8 and 12 years, and colonised with Methicilline Sensitive *Staphylococcus aureus*. First "educative diagnosis" was performed by the dietetitian after an individual briefing with the child using a questionnaire. This allowed to determine "education" objectives for each child. The children then took part in a collective therapeutic education program between September 2005 and 2006, aiming at improving their knowledge on the disease and their sport training. During the session dedicated to nutrition, children worked on following topics: mechanism of digestion, modification of the digestion in CF, general nutrition guidelines and food families, recommendations on how to eat high-energy food. All these workshops of an hour were based on teaching aids such as puzzles, educational game, and activity of cooking. Sport activities were also done by the children. A booklet containing these topics and receipts was given to each child at the end of the session. Evaluation of acquired knowledge was done during the following consultation and at 6 months. Both showed a clear improvement in the knowledge of the disease and self-management for most of the children.

292 CF and Me – a colouring book for children

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Purpose: Information on CF is readily available to families, health professionals and older children with CF. However, there is a lack of quality educational resources for children under 8 years. During the preschool and early school years children have a limited understanding of health and illness. They know little about their internal organs and how they work (Berk, 2003)and usually rely on their parents for explanations. Discussion of medical issues and procedures with younger children can often be extremely difficult. To address this, a colouring book "CF and Me" is being developed. This book will explain CF and its management in an age appropriate manner meeting the cognitive developmental needs of children 4–8 years.
Methods: "CF and Me" has been developed using similar methodology to educational resources previously developed by us for children with cancer "Chemo and Me" (Byrne, 1997) and Asthma "I Have Asthma" (Thomsen, 2003). Main themes in "CF and Me" are: what is CF; physiotherapy; exercise; medications; nebulisers; IV therapy; diet; hospital admission; clinic visits and lung function. We have previously assessed the effectiveness of "I have Asthma" by parental questionnaire.
Results: The questionnaires demonstrated that reading "I Have Asthma" has helped 95% of parents and 80% of children to understand reliever and preventer medications, 86% of parents and 84% of children to use a puffer and spacer, 85% of parents and 65% of children to identify asthma triggers.
Conclusion: Medical colouring books are valuable educational resources for children. It is expected that "CF and Me" will improve understanding of CF in children and their families. We plan to pilot "CF and Me" and assess its value using parental feedback.