View metadata, citation and similar papers at core.ac.uk
brought to you by CORE
provided by Elsevier - Publisher Connector

364 Unexpected side-effects of a clinical trial

J.C. Maddison[1], T.M. McGinnity[1], A.L. Harris[1], J.P. Legg[1], G. Connett[1]. [1]*Southampton University Hospitals NHS Trust, Child Health, Southampton, United Kingdom*

Background: Cystic fibrosis (CF) families routinely have direct access to their clinical CF teams. Families are not routinely contacted regarding new symptoms. We are currently undertaking an interventional trial to which 41 children aged 2 yrs–14 yrs have been recruited. Trial patients receive fortnightly text messages to inquire about cold symptoms and reminding them to contact the research nurse if they have any. Necessary treatment is delivered directly to them.
Issues: Contact patterns of recruited families are closely monitored. 7 families have demonstrated a significantly increased frequency of contact with the research and clinical teams. 3 families had previously failed to report symptoms between clinic visits but now make prompt, appropriate contact with the CF team expediting treatment. Compliance has improved in 1 child taking a more active role in treatment and attendance at routine clinic. 4 families have lost confidence in their ability to interpret symptoms and have repeatedly contacted the teams about symptoms that are not observed on subsequent review. This heightened anxiety has necessitated increased psychological support. Concerns surrounding the accuracy of reporting in these familes has resulted in a reduced threshold for clinical review. No significant clinical, socioeconomic or demographic differences have been identified between the groups.
Conclusion: For some patients regular contact is useful in encouraging identification of symptoms, instigating treatment and overall compliance. For others it causes them to doubt their own judgement and they become dependent on the clinical teams to make decisions. The difficulty is identifying which family will fit into which category.

365 Expectations and needs of cystic fibrosis (CF) patients and the CF center's response

M. Cafaggi[1], M. Marcucci[2], F. Festini[3], C. Braggion[1]. [1]*Meyer Children Hospital, Cystic Fibrosis Center of Tuscany, Florence, Italy;* [2]*Local Heath Company – Tuscan Heath Service, Training Agency, Empoli, Italy;* [3]*University of Florence, Faculty of Medicine, Florence, Italy*

Cystic fibrosis (CF) strongly influences the quality of life of affected people, who need help and support to deal with the difficulties caused by the disease and the therapeutic regimen required. The capability of a CF Center team to give prompt and effective answers to CF patients' needs is paramount.
Aims: To evaluate accessibility and capability to respond to patients' needs and expectations of a CF Center.
Methods: An 11-item ad hoc questionnaire was mailed to all the 247 patients (or their parents if minors) followed by the CF Center of Tuscany.
Results: 87 questionnaires were returned (35.2%, mean age 21 yrs, males 48.3%). Information received about drug side effects were inappropriate for 35.6% of pts; the training received about the treatment regimen and periodical checks was considered inappropriate by 18.7% of pts. Getting drugs for urgent treatments was reported as difficult by 42.5% of pts. Although free according to Italian law, delivery of drugs is slow and difficult for 36.8% of pts. 83.9% of patients consider accurate the clinical reports received after annual checks. 30% have problems with IV therapy and feel restrained in their daily activities (45%). 19.1% pts require an improvement of telephone counseling and 17.5% ask for a single professional reference.
Discussion: Our results suggest that periodical evaluation of patients' expectations and needs and of their perception of the CF Center capability to give them effective responses to patients' needs may help a CF Center's team of care in continuous improvement of the quality of care offered, so that not only a fully evidence-based nursing care but also a need-based nursing care be provided.

366* Cystic fibrosis newborn screening: facilitating family centred care

L. Fairservice[1], L. Semple[2], M. Soles[1]. [1]*Alberta Children's Hospital, Calgary, Canada;* [2]*Mount Royal University, Calgary, Canada*

Follow-up for infants recalled through the Newborn Screening programme in Calgary Alberta, is conducted within the CF clinic at the Alberta Children's Hospital. The CF nurse specialist is responsible for coordinating the care for these infants. Whether the initial NBS report is "possible" or "probable cystic fibrosis", the time between notification of the suspicious results and confirmation with a sweat chloride assay is stressful for parents. The relationship between the nurse and the parents may be short, but intensive and requires an approach based on the family's needs, abilities and situation. Several challenges influence and shape the plan of care. The accuracy of the information obtained by parents in the community prior to meeting with or speaking to the CF nurse can serve as a resource or a source of stress. Clarification of misconceptions is frequently required. The clinic serves a diverse childbearing population, with unpredictable language skills and health literacy. Follow-up for premature or small infants is delayed and may require liaison with NICU staff and community health care professionals. Within the framework of family centered care, successful nursing strategies include sharing of complete unbiased information, acknowledging family perspectives and choices; provision of telephone support, and opportunities for follow-up and clarification. Recommendations for nursing practice include: continued collaboration with community health care professionals to ensure the accuracy of information provided; development of a website to support family education, ongoing awareness and evaluation of the evolving needs of the population.

367 Motivational interviewing (MI); evaluating the learning outcomes of UK CF team training

A. Duff[1,2], G. Latchford[1,3], R. Pieniazek[1]. [1]*Leeds Teaching Hospitals NHS Trust, Clinical & Health Psychology, Leeds, United Kingdom;* [2]*Leeds Teaching Hospitals NHS Trust, Regional Paediatric CF Unit, Leeds, United Kingdom;* [3]*Leeds Teaching Hospitals NHS Trust, Regional Adult CF Unit, Leeds, United Kingdom*

Introduction: MI is an evidence-based therapeutic strategy for enhancing behaviour change, and is particularly relevant for patients who exhibit poor adherence. This study reports long-term learning outcomes from MI training for CF teams across the UK, consisting of one 4-hour workshop on MI principles followed 6 months later by a 2nd, on applying MI in brief sessions.
Methods: 60 health professionals from 7 UK CF teams completed questionnaires on learning outcomes 6 months after the 1st workshop, but before the 2nd. 14 volunteered for telephone-interview 3 months after the 2nd workshop to gather qualitative data. 1-year quantitative follow-up will be complete in May 2011.
Results: *Questionnaire data*: All participants felt they had the potential to develop MI skills. Most (89%) noted improved understanding of adherence and 93% felt MI would improve it. 80% had tried MI with patients since the 1st workshop but at that time, only 53% felt confident in their skills. Almost all (95%) wanted case-based, team-discussion as part of ongoing support/training. *Interview data*: initial analyses reveal great enthusiasm for the potential of MI but concerns about possible barriers to routine use (e.g., lack of time with patients and length of time between visits and the clinical setting).
Conclusions: This study shows that initial MI training with CF team-members results in increased knowledge and confidence about acquiring and applying MI techniques. However this is balanced with consideration of barriers to application, further training needs and ongoing team-based support. Qualitative learning outcome data will be presented in full together with the 2-mth follow-up data.