Correlates of readiness to transfer to adult cystic fibrosis clinics

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Objective: As patients with cystic fibrosis (CF) are living longer, transfer from a pediatric to an adult clinic has become a more challenging issue. Despite increased availability of adult providers, approximately 25% of adults with CF receive care from a pediatrician (Anderson, Flume, Hardy, & Gray, 2002). This study assesses relationships between readiness to transfer and CF-related knowledge, parental distress, and executive and family functioning.

Methods: Participants were patients (n = 50) from three pediatric CF centers in the United States (M age = 15.93 years). Patients completed measures of executive function and CF knowledge. Parents completed measures of demographics, family functioning, and parental distress. Parents, patients, and CF team members rated patients’ readiness to transfer to adult clinic.

Results: In a linear regression model, older age (β = 0.80, p < 0.001) and higher FEV1 (β = 0.37, p < 0.001) were associated with physicians’ ratings of greater readiness, accounting for 60% of the variance (F(3,34) = 16.48, p < 0.001). In separate analyses, worse family functioning (F(1,32) = 7.38, p < 0.001) and greater knowledge (F(3,38) = 10.94, p < 0.001) accounted for significant proportions in nurses’ ratings, after controlling for age and health status.

Conclusions: Older and healthier adolescents were rated as more ready to attend adult clinic. Surprisingly, worse family functioning in relation to transfer may have reflected increased adolescent independence and rebellion. Limitations included small sample size and cross-sectional design. Future studies should investigate longitudinal predictors of successful transition to adult care.

Prevalence of passive exposure to cigarette and active smoking in a large pediatric CF centre in Montreal (Québec, Canada)

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Introduction: Passive exposure to cigarette smoke has been associated with increased hospitalization rates for acute respiratory exacerbations in CF patients and with lower lung function. The objective of this study was to determine the smoking prevalence in parents of CF patients and older patients attending the CF clinic at Hôpital Ste-Justine, Montréal.

Methods: Smoking habits were assessed by an anonymous questionnaire distributed to parents of all patients attending the CF clinic during a routine visit and to all CF patients 10 years of age and older during 2005.

Results: A total of 211 questionnaires were distributed to parents of CF patients and a total of 208 questionnaires were returned (response rate 98%). The overall prevalence rate of parental (mother and/or father) smoking was 45%. Among current smokers, the mean numbers of cigarettes/day was 15 ± 7. Of those patients exposed to second-hand tobacco smoke, 55% were exposed in a close environment (homes +/- cars). Among smokers, 92% agreed that exposure to cigarette may be harmful to the respiratory health of their child, and 78% had made at least an attempt to quit smoking. A total of 122 questionnaires were distributed and completed by CF patients 10 years of age and older. The prevalence of cigarette smoking in these patients was 2%. In year 2005, overall smoking prevalence in the general population was 22% and 17% in teenagers in the province of Québec, 17% of children 0–11 of age were regularly exposed to second-hand smoking.

Conclusions: There exists a high prevalence rate of passive exposure to cigarette in patients with CF that exceeds the prevalence in the general population.

Striving for glycaemic control in cystic fibrosis-related diabetes: a qualitative study

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Aims: Cases of diabetes among people with cystic fibrosis (CF) have increased as their life expectancy improves. This study provides an insight into the efforts of patients with cystic fibrosis-related diabetes (CFRD) to maintain optimal blood glucose (BG) levels.

Methods: As part of a series of qualitative interviews focusing on patients’ management of CFRD, participants were asked to discuss their experiences of high (hyperglycaemia) and low (hypoglycaemia) BG. Data were collected via semi-structured interviews, which were taped, transcribed and analysed using a framework approach.

Results: 11 CFRD patients were interviewed. Four themes were derived from the analysis: 1. Putting the management of BG into perspective – people interviewed had no experience of severe hypoglycaemia (needing outside assistance) and, generally, felt they had more control over diabetes than over CF; 2. The unpredictability of BG – participants managed this uncertainty through personalised routines and taking precautions; 3. The interaction between BG and CF – interviewees were concerned if their BG was high, fearing this indicated a problem with their chest, yet not all were vigilant in checking their sugars; 4. Personal awareness of changes in BG – people described specific signs indicating high and low BG and particular triggers affecting glycaemic control.

Conclusions: Participants found it easier to manage diabetes when able to maintain a routine in terms of treatment and monitoring, yet some resented the restrictions this placed on their daily living. Coping with an existing chronic condition prepared them for the self-care of diabetes, but they were frustrated at having another illness to control.

Segregated hospitalisation – the carer perspective

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Introduction: This paper presents the results of a qualitative study of CF family carers at the Belfast Paediatric CF Centre. The aim of this study was to describe the carer experience of their child’s admission to hospital under segregated care arrangements, and to highlight the meaning of segregation and cross infection from the carer perspective.

Method: Carers of children with CF who were admitted for two week IV antibiotic treatment during the study period were eligible to participate in this qualitative study. A consecutive series of eligible carers were approached in order of admission and within the time constraints of KR who was present two days each week. Recruitment of carers ended when no new themes emerged. Ten carers, 9 mothers and 1 couple, were interviewed about their experiences (mean age of child: 11.8 years; range: 1–17 years). Interpretative Phenomenological Analysis (IPA) was used to analyse and interpret the interview data.

Results and Discussion: Balancing demands and dilemmas was the main contextual theme or experience of being a carer of a child with CF, and particularly so during admission to hospital. Many decisions were required every day that resulted in ‘double binds’ comprising uncertainty and stress. Three secondary themes captured the essence of carers’ experiences specifically related to segregation: managing risk and uncertainty, the burden of admission, and getting through each day. These themes will be described with examples illustrating the challenges faced by carers during their child’s hospitalisation, and the impact of segregation upon carers.