What level of understanding do preschool age children screened for cystic fibrosis have of their disease?  

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Conversely to cystic fibrosis (CF) diagnosis based on symptoms, in CF newborn screening (NBS) programmes, initial parental information on CF and follow-up care are incorporated into family life very early.

Aim: To assess the knowledge of preschool age CF (PSA-CF) patients and the information parents believe the children understand.

Method: Over a three-month period, face-to-face interviews and questionnaires were conducted by a psychologist with the parents and with PSA-CF patients born between 2002 and 2006.

Results: 22 children (13F; 9M) out of 24 were included as well as 4 fathers, 14 mothers and 4 couples. 16 children were able to understand the questions (mean age 4 years). No parental refusal was observed. Parents believe the child was aware of the reason for the hospital visit in 94%, could cite “CF” in 62% and its genetic aetiology in 6%. In fact the actual results in children were 62%, 44% and 6%. Some 62% of parents and children expressed a desire for more information and up to 95% for educational resources. For parents the ideal age for CF disclosure ranged from infant to 8 y with a mean at 3.7 y. Children cope adequately with their daily treatment, hospital visits and chest physiotherapy in 76%, 70% and 63%.

Conclusion: Findings highlight discrepancies between PSA-CF patients’ knowledge of their disease and parents perceptions. We emphasize the need for improving therapeutic education in patients’ age range.

Personality, psychosocial and socioeconomic factors predict adherence behaviour in cystic fibrosis (CF) adults

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Adherence to treatment is influenced by many factors and is critical to optimal CF management. Psychosocial factors are emerging as strong predictors of adherence behaviour.

Aim: To explore personality, psychosocial and socioeconomic factors and their association with adherence behaviour in CF patients.

Methodology: Demographic, health related measures, socioeconomic, and questionnaires investigating personality (NEO-PI), psychosocial (depression, anxiety, social support, health locus of control, life stressors, quality of life and health beliefs) and adherence behaviour (Morsisky Score and Beliefs and Behaviour Questionnaire (BBQ)) were obtained at the commencement of electronically monitored treatment with azithromycin.

Results: To date 67 participants (mean years = 33.9 yrs, SD = 9.7 range 20–68) males 53%, mean FEV1 % predicted = 57.2 SD ±20.6, range 19–115) have been recruited. A significant correlation was observed between Morsisky score and BBQ self-reported adherence measures ($r^2 = 0.27$, $p < 0.01$). The psychosocial factors that were related to reported adherence were consciousness ($r^2 = 0.45$, $p < 0.001$), anxiety ($r^2 = 0.25$ $p < 0.001$) anxiety and depression ($r^2 = −0.25$ $p < 0.04$) and stressful life events ($r^2 = 0.23$ $p < 0.001$). Using census-derived (SEIFA) data, FEV1 % predicted at baseline was dependent on socio-economic status scores ($r^2 = 0.27$, $p < 0.03$). In addition, FEV1 % predicted was dependent on education and occupation scores ($r^2 = 0.33$, $p < 0.009$).

Conclusion: Skilled assessment and consideration of multiple psychological factors may be beneficial in optimizing adherence to treatment plans in CF patients.

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A qualitative study of cystic fibrosis (CF) patients’ expectations of gene therapy

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Introduction: The UK CF Gene Therapy Consortium (funded by the CF Trust) is preparing for a multi-dose gene therapy trial which may produce some clinical benefits.

Aims: The current study explores the expectations of CF patients involved in the pre-treatment phase of this gene therapy trial (the “Run-in study”), from which participants will be selected for the multi-dose gene therapy trial.

Method: Semi-structured interviews were conducted with twelve participants (six with mild and six with moderate CF). Interviews were recorded, transcribed verbatim and analysed using a Constructivist Grounded Theory approach.

Results: The reality of clinical benefit from gene therapy is growing for participants and this may be beneficial in optimizing adherence to treatment plans in CF patients.

Illness perception does not predict treatment concordance in adults with cystic fibrosis

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Poor concordance with medical treatment is common in chronic illnesses, including CF. The reasons for poor concordance are not well understood. The application of theoretical models have met with limited success. Abbott et al found some support for the “health locus of control” model but not the “health belief” model. New models suggest that “illness representations” are linked with concordance. Weinmann et al developed the brief illness perception questionnaire, scores have been shown to be linked to health behaviours in other conditions.

Methods: All 115 adult CF patients attending our clinic were invited to take part. Participants were asked to complete an anonymous questionnaire whilst attending clinic or at home. Concordance was measured by disclosing how often each treatment was taken on the following scale: always, most of the time, occasionally or never. The brief illness perception questionnaire was then completed. Basic patient demographics and the reasons for poor concordance were also recorded.

Results: 64 patients took part. Reported concordance was highest for azithromycin and cream followed by vitamins and nebulised antibiotics. Concordance was lowest for supplementary feeds. Illness perception was not linked to poor concordance for any of the treatments. Those with children or in the 18 to 25 year age group were more likely to have poor concordance. Forgetfulness was the commonest reason cited for non-concordance.

Conclusions: These results suggest that illness perception is similar amongst those who comply with their treatment and those who do not, challenging our ideas of what influences patient concordance.