The development of the Cystic Fibrosis Impact of Diagnosis Scale (CFID)

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Parents of children newly diagnosed with Cystic Fibrosis can experience an enormous amount of stress due to the demands of the child’s disease. Outcome measures that have been developed to measure parental stress are typically designed for parents of children that do not have a chronic disease. Other available outcome measures are generic instruments that measure stress in parents of a child with a chronic disease but are not disease specific. A large part of the literature focuses on the patient and their disease and not the parent caring for the child with the chronic disease. The aims of this study were to therefore develop and pilot test an instrument that assessed stress in parents of newly diagnosed infants with CF. The CFID was developed with the input of a specialist group, expert panel and target population of parents with children that had been diagnosed with CF at The Royal Children’s Hospital, Melbourne. The CFID was pilot tested on a small sample of 13 parents (response rate 85.7%). All participants were female Caucasians aged between 26 and 44 years (mean 34.4, sd 5.4). Three of the 13 participants had babies that were less than 6 months old, and the other 10 participants had children that were 8 months of age or older. The mean total score for the participants responses to the 36 items of the CFID was 58.6 (sd 23.3, range 22-89), with a possible total score of 144. In this study, Cronbach’s alpha and item-total correlations were used as strategies for exploring the homogeneity of the CFID. The alpha was 0.92 which may suggest item redundancy. It is anticipated that the CFID be used in clinical practice as a screening tool to determine the impact of the diagnosis of CF in the parents of the infant, and assist the parents accordingly. Further testing and analysis of validity and test-retest reliability is needed. In order to recruit the sample size needed for such investigations research including CF centres across Australia would be required to participate.

Managing ‘normality’ and CF during adolescence: a qualitative study

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Aims: This study aimed to explore the meaning that adolescents with CF attach to their illness-related experiences.

Method: The qualitative methodology of Interpretative Phenomenological Analysis was used. Ten semi-structured interviews were conducted with adolescents aged 12 to 16. The interview transcripts were analysed in fine detail, with the aim of exploring the meanings that particular CF-related experiences and states held for participants in the context of their personal and social worlds. In the final stage of the analysis, closely related themes from all the participants were grouped together in a summary list to describe their collective content.

Results: The following themes will be discussed in this presentation:
1. Alone in a crowd.
   a. Being the only one.
   b. Telling others.
2. Beyond duality: Fostering acceptance.

Conclusions: The adolescents’ accounts allowed for an insight into the ways in which they were making sense of their ‘uniqueness’. In the peer context, participants seemed to be regulating the effects of being different by controlling the extent to which the ‘invisible’ aspects of their CF became ‘visible’ to others. Differences were illustrated between the female and male participants’ use of their close friendships as a means of support. The interviews illustrated participants’ attempts at managing intrapersonal and interpersonal implications of being simultaneously ‘normal’ adolescents and ‘CF patients’. The manner in which this duality manifested itself in the adolescents’ accounts is considered. The adolescents that accepted CF as an integral part of their selves seemed to move away from focusing on limitations to embracing what was possible. These findings, and their clinical implications, are discussed in relation to literature on developmental transitions and chronic illness.

When does poor parental adherence with their child’s CF care become a child protection issue?

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Modern CF management regimens require many different treatments several times a day. Although the majority of parents of children with CF cope with the burden of care, some children are denied optimal therapy by their parents’ inability or unwillingness to adhere to prescribed treatment regimens. We report eight cases from two UK Regional CF Centres that illustrate the challenges involved for multidisciplinary teams in this difficult area. In three cases child protection proceedings were instigated for neglect. The children were moved into foster care with subsequent improvement in clinical status. The mother of a fourth child failed to understand the necessary complexities of CF care. The CF Team responded by arranging a respite carer for home intravenous antibiotic therapy treatments. A fifth child was persistently not brought to clinic appointments. Child protection proceedings were successfully used as a last resort to improve attendance. Three additional cases will be presented where there were concerns of inadequate parenting affecting treatment at home, but insufficient evidence to warrant formal child-protection proceedings. We highlight a sensitive and difficult area in paediatric CF management, and discuss indicators associated with sub-optimal parental care. The CF team must place the rights of the child above all else but balance the right to optimal treatment with the benefits of living in a loving and secure family environment. An inappropriate use of child-protection proceedings may damage the relationship between the parents and the CF Team, to the detriment, rather than the benefit, of the affected child.

Stress perception, stress management, and perceived disease impact among 10- to 14-year-old CF youngsters

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Aims: Today, parents of CF children are encouraged to let their children live a normal life. However, incorporating a chronic disease into a normal daily life may well be a difficult, stressful, and sometimes overloading task. The aim of this part of the study was to assess the perceived stress, the management of stress as well as the perceived disease impact.

Methods: Cross-sectional case-control design; the stress perception and management were assessed by the SSK, a well established German scale. Disease impact was assessed by a six item questionnaire designed for the purpose of the study.

Sample: N = 47 CF children; the lower response rate in the control group allowed for analysis of 25 complete pairs.

Results: There were no differences between the groups neither to perceived stress, nor type of stress management (seeking social support, problem-solving, emotional coping), nor amount of stress symptoms. Perceived disease impact among the CF youngsters (n = 47) showed positive estimates for all items, with particularly positive scores regarding impact on school performance and on friendships (53%/61% declared having no disease-related problems at all). Perceived disease impact was significantly correlated with stress perception and amount of stress symptoms (r = 0.53/r = 0.66, respectively; p < 0.001) but not with type of stress management. Also, disease impact was higher in youngsters with low weight for height (r = 0.3; p = 0.05) and chronic Pseudomonas lung infection (r = 0.32; p < 0.05).

Conclusions: Despite their disease related burden CF youngsters display a similar stress profile as their peers.