

285 A second chronic illness: how do adults with CF experience being diagnosed with diabetes?

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Diabetes is a common complication in adults with CF.

Aim: To examine the experience of adults with CF in managing their initial diagnosis of diabetes.

Method: A qualitative single occasion interview design was used, guided by the principles of interpretative phenomenological analysis (IPA). IPA recognises research is a dynamic process where one is trying to take an insider's perspective. 22 adults with CFRD (10 female, mean age 34 years, duration diabetes 1–35 years) were recruited from this centre. Semi-structured interviews using a topic guide drawn from current literature took place; these were recorded and transcribed verbatim.

Results: The four recurring themes identified were; emotional responses, looking for an understanding, learning to live with diabetes and limiting the impact of diagnosis.

Conclusions: The initial diagnosis was met with shock, anxiety, uncertainty and relief. A lack of awareness about diabetes at the time of diagnosis was highlighted. However participants described eventually reaching a level of acceptance with their diabetes. This study showed that adults with CF manage the additional impact of diabetes, its associated managements and treatments relatively well. Healthcare professional should ensure that adults with CF are provided with adequate education and support at the time of the diagnosis of diabetes and that this is ongoing throughout the course of their disease.

287 Effects of a clinic-based intervention on knowledge and treatment skills for parents and young children with CF

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Prior research indicates that illness-related knowledge impacts treatment adherence and health outcomes in children with CF. This intervention aimed to assess and remediate parent and children knowledge of CF and skills associated with daily treatments. A second objective was to examine the relationship between CF knowledge, skills and rates of treatment adherence.

Methods: As part of a larger intervention study at 3 CF Centers, 88 children with CF ages 1 to 11 and their parents participated. Parents and children 6 years of age and older completed a CF Knowledge Questionnaire at enrollment. The family then participated in a series of brief interventions, including 6 clinic sessions and 3 telephone contacts. Treatment skills for airway clearance, nebulized treatments, and enzyme administration were also taught to children and families. Parents demonstrated these skills and if errors occurred, the parent/child dyad was re-taught the skills until mastery was obtained. Knowledge and skills were then re-evaluated at the end of the intervention.

Results: Prior to the intervention, substantial gaps in knowledge were identified. Parents answered 60% of the questions correctly and children answered 43% correctly. Controlling for maternal education and child age, parents' knowledge increased by 6 points ($p < 0.05$) and children increased by 11 points ($p < 0.05$). Changes in treatment skills are still being evaluated.

Conclusions: Significant improvements were found in CF-related knowledge for both parents and children. However, gaps in knowledge remain and should be addressed. Changes in treatment skills will also be presented.

Funding was provided by NIH grant #69736.

286 Perceptions of young people with CF on the lack of knowledge and understanding of the condition within the general public

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Introduction: A qualitative study examining transition to adulthood for young people with CF.

Method: In-depth semi-structured interviews were conducted with 8 male and 10 female CF patients aged 16–21 years. The study has been conducted and is currently being analysed using Grounded Theory.

Results: A prominent theme to emerge is that participants felt there is very little knowledge and understanding of CF amongst those not directly affected by the condition. They related this to the minimal media attention they feel CF receives. For many this had an impact on decisions of whether to disclose the condition to peers as they found explaining the condition difficult and embarrassing.

Participants felt information about CF in the media has a tendency to be inaccurate and overly negative. They believe this contributes to a lack of understanding about CF and evokes feelings of sympathy towards those with the condition, which angered many of the young people. There was consensus that the media has thus far failed to present an accurate portrayal of what it means to be a young person living with CF.

Discussion: Young people with CF are concerned about the perceptions of the general public regarding their condition. This can adversely affect their relationship with peers. However, contrary to the negative picture participants feel is portrayed by the media, analysis of this study has painted a positive picture of a group of young people with CF who use a number of strategies to live their lives as normally as possible and achieve the many aspirations they have for the future.

288 Mediating and negotiating and in-patient stay for families and patients with cystic fibrosis

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Reviews of the literature and discussions with staff, patients and families reveal a complex array of difficulties associated with the long-term psycho/social in-patient management of a chronic illness such as cystic fibrosis. Families/patients can bring unresolved concerns and conflict from past admissions. These are regularly expressed in terms of having little power or control in relation to the general management of the/their illness.

Staff also speak of a loss of professional role, and feelings of impotence and frustration are not uncommon for staff when working with families/patients who are perceived as difficult.

A level of stalemate can then develop for both families/patients and staff who can be unsure how to work more collaboratively and effectively together.

Systems theory can be used to identify and analyse areas of conflict, and structure a process of mediation and negotiation between families/patients and staff.

Systems theory examines the inter-subjective relationship between individuals, the way in which they communicate, and the meanings that develop out of these interactions. This theoretical and therapeutic tool affords the opportunity to understand and analyse past patterns between patients/families and staff. This then allows for the development of assessment tools which subsequently support appropriate interventions and collaboration between all parties. The results of this research indicate that the utilization of this model, during an in-patient stay, has a positive impact on how cystic fibrosis is managed by staff, families and patients.