

258 A qualitative study exploring the needs of mothers and fathers with CF

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Objectives: More people with CF are having the opportunity to become parents. However, there is limited understanding of how parents cope with the dual roles of parenting and being a person with CF. In order to understand how best to provide psychosocial support to these patients, a qualitative study was undertaken within the All Wales Adult CF Service to gain an understanding of the needs of these parents.

Methods: A total of 5 mothers and 4 fathers with CF (mean FEV1 70.2%; range 40–50 to 91–100%) were recruited purposively and undertook a semi-structured interview of 90 minutes. Questions focused on the interaction between parenting and living with CF. Interview transcripts were analysed using interpretive phenomenological analysis to create themes.

Results: Parenting and being a person with CF are both time consuming roles and invested with powerful expectations to undertake them successfully. Parents described a new perspective on keeping well. Despite this, many mothers reported putting their young children's needs first when faced with separation from their child for a hospital admission or time consuming treatment. Therefore, many endured feeling physically unwell, frightened and anxious about their health.

However, most fathers prioritised CF treatment with a view to more time with their family in the long term. Fathers were more likely to experience 'missing out', sadness and frustration within their parental role.

Conclusion: Parents were knowledgeable about CF treatment but faced difficult choices when prioritising health and care of their children. These findings will be used to improve services to meet the needs of both mothers and fathers with CF.

259 Parenting stress in mothers with cystic fibrosis

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Objectives: To assess parenting stress in mothers with CF caring for children aged 1 y-12 y and to compare with normative data.

Methods: Cross-sectional, mixed-methods study (qualitative and quantitative measures); the present part of the study is based on data assessed with a validated generic parental stress questionnaire [PSQ] ("Elternstressfragebogen", Lohaus & Domsch 2010). Based on a transactional concept of stress, this PSQ differentiates four components: parental stress, contributing factors, protective factors (two scales). Cut-off scores categorize results as 'normal', 'borderline' or 'concerning' (i.e. requiring further assessment).

Sample: 73 women were informed by their local CF centre. Of these, 38 actually enrolled and 31 had a first-born child aged 1 y-12 y (consistent with reference values of the PSQ).

Results: Parental stress scores were normally distributed, the same applies for contributing factors and for the two protective factors. Mothers of younger children scored slightly better than mothers of school-aged children. Very "positive" scores (i.e. very high protective impact, very low stress or contributing impact) were twice as frequent as "negative", concerning scores (i.e. very low protective impact, very high stress or contributing impact).

Conclusion: In line with the only comparable study (Frankl & Hjelte. *J Cyst Fibros*, Vol. 3, Suppl. 1, p. 103; 2004), mothers with CF seem to be a remarkably resilient group who mostly cope well with parental stress even in the face of a progressive, time-consuming chronic disease.

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260 A prospective cohort study examining the prevalence of emotional and behavioural difficulties in children of patients with cystic fibrosis (CF)

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Objectives: As life expectancy of people with CF continues to rise, more of our patients are becoming parents. There is evidence that parental ill health can affect the emotional and behavioural development of children, but we are not aware of previous research investigating this in the CF population.

Methods: We conducted a prospective study, recording parental measures of mental health (Hospital Anxiety and Depression Scale), physical health (BMI, FEV₁) and sociodemographic data in our large regional adult CF centre. Child information was obtained using the parent-reported Strengths and Difficulties Questionnaire (SDQ), a validated behavioural screening questionnaire.

Results: Data was obtained from 17 parents of 21 children (mean age = 7.7, range 3–16 years). Parental anxiety and depression was correlated with childhood overall stress ($r = 0.44$, $p = 0.045$; $r = 0.48$, $p = 0.027$ respectively). Parental depression was also associated with childhood emotional distress ($r = 0.53$, $p = 0.013$). Partial correlational analysis showed that some relationships ceased to be significant when lung function was controlled for. Similarly, children with both emotional distress and overall stress differed from those without, with respect to parental depression. Consistent with previous findings, lower parental education was associated with greater levels of overall child stress.

Conclusion: Parental mental health problems, both anxiety and depression, were associated with childhood stress. Future research should investigate other mediating variables such as family support, consider the child's behaviour and emotions from their own perspective, and utilise qualitative methods.

261 Planning for pre-implantation diagnosis: a qualitative study

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Objectives: In the last 20 years it has become possible for individuals who are affected by a genetic disease to undergo pre implantation genetic diagnosis (PGD). The method is since 2005 eligible in Sweden for cystic fibrosis (CF). Ten CF carrier couples have so far undergone PGD with the results of seven children. The aim was to provide an increased understanding of the decision to undergo PGD.

Methods: A qualitative interview study with 19 couples all planning and eligible for PGD at Reproductive Medicine. Ten of the couples carried genes for monogenetic diseases such as dystrophia myotonica and Fragile X, and nine couples had chromosomal disorders. No couples with CF were eligible during inclusion (2010–2011). Analysis was performed with a thematic approach.

Results: The analysis led to the formation of a master theme, labeled choosing. In addition three subthemes were emerged: In relation to myself, In relation to the child, and In relation the surrounding and nine underlying categories. No differences were found between men and women concerning emotional depth or cognitive recognition of the decision. No differences were found related to diagnosis.

Conclusion: The men and women in this study were a heterogenic group with great variations in reproductive history. However, they expressed common themes about what affected them in their decision to undergo PGD. The themes are complex and activate ethical reasoning. The results of this present study are relevant for pre PGD-counseling, and indicate that support should be provided. This knowledge about the choice and demand for support are generalizable to couples carrying the gene for CF and seeking for PGD.