Fathers' experiences of the emotional impact of managing the care of their children with cystic fibrosis (CF)

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**Background:** Few studies have consulted fathers of ill children. Limited research on fathers of children with chronic illnesses, however, has identified that they experience more worries and concerns (Hovey, 2003) and express more feelings of lower self esteem (Katz and Krulik, 1999) than fathers of well children.

**Aim:** To explore fathers' experiences of the emotional impact of managing the care of their children with CF.

**Method:** Eight Irish fathers of preschool children with CF took part in audio-taped structured interviews involving patients aged from two to twenty-one years old and living in a regional setting.

**Data incorporating personal accounts, drawings and poetry was drawn from un-anonymous, semi-structured questionnaire. The questionnaire was self administered and contained 15 items. The questions related to prevalence, onset, precipitating factors, severity of symptoms plus the physical, social and emotional impact of USI. Issues related to seeking management of this problem were also explored.

**Results:** Response rate was 70% (n = 107). Prevalence of USI in last year was 55% (n = 56). Onset 16-20 years 36% (n = 21), 21-25 years 14% (n = 8), 26-30 years 9% (n = 5), 31-35 years 7% (n = 4), 36-40 years 7% (n = 4), and 40 years+ 3% (n = 5). The greatest precipitating factors causing mild symptoms (a few drops of leaked urine) was sneezing 81% (n = 47) and those causing moderate to severe symptoms (change of underwear to emptying whole bladder) was coughing 43% (n = 25). The most common activities that patients avoided due to USI were laughing 27% (n = 16) and coughing 24% (n = 14). 79% (n = 46) of patients reported that USI never or rarely interfered with their life. 12% (n = 7) reported quite frequently to frequency and 3% (n = 3) reported very frequently to all the time. 21% (n = 12) of patients had sought help or treatment for this condition. 78% (n = 45) of patients had not done so and the most common reason for this was due to unawareness of treatment 19% (n = 11) and 22% (n = 13) felt that USI was not as serious a condition as CF.

**Conclusion:** This study confirms a high prevalence and impact of USI in an adult female CF population.

The voice of experience: listening to those who live with Cystic Fibrosis

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**Aims:** This study investigated the daily experience of CF patients and their parents living in a regional setting.

**Methods:** A qualitative methodology – interpretative phenomenology – was used. Data incorporating personal accounts, drawings and poetry was drawn from unstructured interviews involving patients aged from two to twenty-one years old and their parents.

**Results:** Analysis uncovered eight distinct themes that framed participants’ experience: original fright, through ongoing dynamics of fight and flight, redefined notions of form, familiarity and philosophy, in the pursuit of a future that is both threatened and continually redefined. Of particular magnitude were parents’ struggles in the search for new and accurate bearings of information, support and services. Children revealed growing awareness of, and adaptation to, life with CF. Young adults spoke of negotiating adolescence attended by extraordinary issues such as adherence, death of friends, and lung transplantation.

**Conclusion:** Giving voice to the circumstances and concerns confronting these families has rendered significant insight. As a result of enhanced knowledge, care can be strategically designed and delivered.