

**402 Experiences, perceptions and assessments of medical treatment among patients with CF**

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The objective of this study was to achieve an understanding of the experiences, perceptions and assessments of medical treatment among adult CF patients, regarding their medical treatment and in relation to their everyday life. Data was collected through ten semi-structured interviews. The analysis showed varying views and experiences with disease and treatment, nevertheless there were common characteristics. Most patients had experienced defeat through life under education, with career and when founding a family. They all emphasized being like everyone else, and therefore it was hard for them to accept the disease and the limitations that follows. Acceptance of the disease proved particularly important, as acceptance made the treatment a daily chore instead of a daily irritation. A correlation between disease acceptance and contact with fellow patients was shown. This contact was described as a unique opportunity to exchange knowledge, and as a source of mutual understanding. A few patients chose to distance themselves from other patients to avoid being reminded of their disease and its seriousness. The medical treatment was found very time consuming and often not compatible with a regular life. All patients expressed the wish to live a normal life with education, job, family and friends. The acceptance and understanding among patients surroundings is of great importance.

**403 Are the psychosocial needs of cystic fibrosis patients being met post-transplant?**

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**Background:** Lung transplantation is an effective means for improving survival and quality of life in patients with CF with end-stage lung disease, but little is known about psychosocial needs post transplant. In Leeds, patients receive intense psychosocial and medical input prior to transplant which is reduced after a successful transplant. Biennial assessments conducted by the team Clinical Psychologist have suggested that for some this change in support may have an adverse impact. This study aimed to explore the psychosocial impact of lung transplantation and whether psychosocial needs are being met.

**Method:** Invitations to participate were sent to the Unit's post transplant patients. Those consenting took part in a semi structured interview via telephone, which was then subjected to thematic analysis.

**Results:** 15 out of the 30 contacted agreed to take part. Results showed all participants experienced a positive change in quality of life post-transplant, though six also reported additional and sometimes unanticipated problems, e.g. side effects of anti-rejection medication. Many described a process of psychological adjustment following transplant, with three highlighting continuing problems relating to guilt. Seven were unaware that psychosocial support was still available post transplant from the CF team, and five had attempted to access this support elsewhere. Many expressed the sense that as they were now "well", they should not be using resources at the unit.

**Conclusions:** A positive change in quality of life post transplant does not necessarily mean an absence of any psychosocial problems. Routine psychosocial follow up of post-transplant is recommended.

**404 The use of concept mapping in helping to understand the representations of patients with indication of transplantation: a pilot study**

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**Introduction:** Patients' representations about transplantation are unknown. Negative representations could constitute a higher risk for the patients.

**Objectives:**

- To make the patients' and close friends or family's representations explicit
- To make doctor's representations explicit
- To analyse the gap between the patient's and doctor's representations

**Methods:**

- To realize two conceptual maps by interviewing 30 adult patients. One done at the time the question of transplantation is evoked and the second, one year after transplantation. Then analyse the evolution of their representations.
- To realize one conceptual map for 30 patients' close friends or family
- To realize one conceptual map with 30 doctors of CRCM adults then analyse the differences between the conceptual maps of patients close friends or family and doctors.

Thirty-two French CRCM Adults were contacted and 29 agreed to take part in this research. In January 2010, 31 conceptual maps were done with 11 patients, 10 close friends or family and 10 doctors. Patients and accompanying people were very interested in this interview which was, most of time very enriching and with much emotion. After the interview, patients find it easier to ask more questions to the medical team.

**Conclusion:** The results of this study might encourage a clearer choice from patients regarding transplant surgery. We therefore think that after further study of these maps; we will be able to improve the accompaniment of the patients, which will be more centred on their needs before transplantation.

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**405 Tracheal suctioning as an alternative method for sputum sampling in adult CF patients**

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**Background:** Sputum sampling is an important part of CF follow up. However, sputum samples are often not representative and some patients are not able to expectorate an adequate specimen. An alternative method, tracheal suctioning (TS) is to some extent used in new-borns and children, but rarely in adults, and mostly performed by physicians.

**Aim:** To investigate if tracheal suctioning is a tolerable and effective nursing method for detection of airway infection.

**Methods:** We use a modified version of TS as described in NURSING, Lippincott Williams & Wilkins 2007; p 474. In our method we initially ask the patient to rinse the mouth with water, inhale deeply while we insert the catheter via larynx for only 2-5 seconds with applied suction during first 5 cm of removal. The tolerability of TS and representativity of the samples in TS are investigated. In patients who expectorate voluntarily, an initial sputum sample is collected and the microbial results are compared to TS. We aim to include all adult CF patients in our centre (n = 34).

**Results:** So far, TS has been performed in 10 adult CF patients, in some patients repeatedly. No serious adverse events have occurred. The most common complaint is a transient feeling of vomiting, mild cough and dyspnoe. The procedure is completed in <5 minutes. All samples were representative. The representativity and microbial results of TS and sputum samples appear similar in preliminary analyses.

**Conclusion:** Tracheal suctioning seems to be a quick, tolerable and reliable method for sputum sampling. Whether TS is superior to sputum sampling, remains to be investigated.