The prevalence of substance abuse in cystic fibrosis

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Background: Substance abuse is very prevalent in today’s society and has numerous consequences on the physical and psychological health of individuals. Little is known about the prevalence of substance abuse in patients with chronic diseases. Cystic fibrosis is the most common lethal genetic disease in Caucasian populations. Previous research on substance abuse in patients with CF is limited. Given the serious nature of the illness and the multiple body systems involved, understanding more about substance abuse in CF could have significant implications for the health and treatment of these patients.

Objectives: The purpose of our study was to determine the prevalence of substance abuse in cystic fibrosis patients.

Methods: Participants were recruited from the Calgary Adult Cystic Fibrosis Clinic and informed consent was obtained. Participants completed a demographics questionnaire, the AUDIT (alcohol use disorders identification test) and the DAST (drug abuse screening test).

Results/conclusions: A total of 100 participants (57 females, 43 males) with CF completed the study. The average age of participants was 28.9. The prevalence of alcohol abuse was 16% and the prevalence of drug abuse was 4%. In our study 82% of participants drank alcohol in the past year, 20% used drugs in the past year and 5% smoked cigarettes regularly. Only 3.2% of the sample had addiction treatment in the past year and 5% smoked cigarettes regularly. 1% of participants admitted overusing pain medications. Only 3.2% of the sample had addiction treatment in the past year. Information gathered from this study could be used to inform and encourage clinicians to ask about substance use in this population. This could lead to earlier detection and treatment for these patients which may improve outcomes.

Outcomes of patients with cystic fibrosis admitted to an intensive care unit

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Objective: Describe the indications for care and outcomes of cystic fibrosis (CF) patients admitted to an intensive care unit.

Methods: Retrospective chart review.

Results: Between 2005 and 2009 18 patients had 20 admissions to the medical intensive care unit (ICU) service at the University of Utah Hospital. The reasons for admission were hemoptysis 5 (25%), CF exacerbation/respiratory failure 13 (65%), pneumothorax 1 (5%), and medication overdose 1 (5%). Assisted ventilation was required in 13 (65%) patients. This was in the form of non-invasive ventilation (NIV) in 11 (55%) and intubation and mechanical ventilation in 7 (35%). Four of the patients receiving NIV went on to intubation. The median ICU length of stay was 1.5 days with a range of 1 to 55 days. ICU and hospital survival were 75% and 70% respectively. Ninety day and one-year survival were 68% and 63% respectively with one patient lost to follow up. Causes of respiratory failure resulting in intubation were hemoptysis (2, both survived), medication overdose (1, survived), and CF exacerbation (4, 1 survived who was transplanted). All patients admitted with hemoptysis were alive one year after the ICU admission. Of the patients admitted with a CF exacerbation/respiratory failure one-year survival was 50% with one patient lost to follow up.

Conclusions: The majority of CF patients requiring intensive care described here had a brief ICU stay. The majority of patients survived the ICU admission, hospitalization, and were alive at one-year follow-up.

Educational needs for transplanted cystic fibrosis patients

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Introduction: After lung transplantation, cystic fibrosis patients have a lot of new skills to acquire: new medications, risks of new emergency situations, rejections, and infections.

Objectives: This study is to clarify the needs in therapeutic education for these patients. Since 2009, 43 adult patients, followed in 6 French transplant centres, have been enrolled and have realised an interview called “educational diagnosis”.

Methods: Educational diagnosis has four parts:
- general interview that explores several dimensions: biomedical, socio-professional and cognitive
- visual evaluation of quality of life on analogical scale
- several questions about the role of medications and a self-measure of adhesion to these treatments
- knowledge questionnaire.

Results: This exhaustive interview shows that most of patients would like to meet more often social workers to help them manage time at work. Needs in psychologists treatments are also commonly identified. Most patients have excellent adherence to immunosuppressive therapy but do not regularly take the other medications: for example, pancreatic enzymes, vitamins, inhaled treatments. They forgot the roles of these drugs. Difficulties in adapting to some situations have been remarked as “what I must do if I forget my immunosuppressive treatment” or “if I vomit”. Diabetic patients need specific educational sessions.

Conclusion: To answer questions identified by the “educational diagnosis”, we have developed pedagogic tools that are proposed to these patients. The study is on going to assess interest of educational sessions with these tools.

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Surviving but stigmatised: making sense of living with Burkholderia cepacia

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Objectives: Infection control policies recommend segregation of people with CF according to bacterial status. This involves isolating those with cepacia from all others in order to prevent cross infection. Service user reports suggest that emotions like anxiety and anger are aroused when those with cepacia are faced with cross infection measures (UK CF Trust, 2009). No studies to date investigate this anecdotal emotional reaction.

Methods and Results: This research was conducted to ask what it is like to live with cepacia, using in depth interviews. A phenomenological approach was used. Three themes appeared to characterise the experience of living with cepacia: 1. Lost identity – Cepacia can challenge one’s self identity, and along with cross infection measures lead to feeling objectified and even alienated from the CF group identity. 2. Status: Condemned – Being colonised with cepacia brings with it knowledge of a restricted future and an imagined death. There is loss of normality and hope. 3. I am cepacia – Decisions about preventing cross infection is influenced by medical knowledge as well as human emotions and social information; therefore adherence to these measures is fluid and contextual.

Conclusion: These themes have real world clinical implications for all CF services, where preventing the spread of cepacia is paramount. Responsibility for cross infection is a burden and requires understanding from both those living with and without cepacia – we need to see beyond the bacteria to the person.