413 Decision-making about pregnancy for women with CF

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Aims: Many young women with CF are now in a position to consider pregnancy. Yet, there is a paucity of literature exploring the issues and dilemmas that they face when making pregnancy-related decisions.
Methods: We used Grounded Theory, a well-validated qualitative methodology, to generate data about the decision-making processes experienced by women with CF (N = 12; age range, 18–30 years) when considering pregnancy. Participants underwent semi-structured interviews and completed self-report measures of quality of life (SF-36; CFQoL), and psychological well-being (HADS). Health and treatment data was collected from hospital records.
Results: Quantitative data indicated that the current sample do not differ significantly from other samples, particularly those likely to be considering pregnancy. Scores on domains sensitive to disease severity suggest the group may have less severe disease and higher psychological functioning than many women with CF. Some elevated anxiety was indicated. A hierarchical model emerged comprising four core categories: (i) the impact of the decision; (ii) preparation for making, and living with, the decision; (iii) owning the decision, and (iv) personal factors. Contained within these, were a number of influential and reciprocal conceptual subcategories, including the impact of pregnancy on health and upon ability to care for the child, pregnancy experiences of other women with CF, moral implications of having a child, and the support and views of family members.
Conclusions: Our findings extend current knowledge, which previously has focused primarily on medical management. Clinical implications are discussed, together with directions for further research.

414 Pregnancy in Cystic Fibrosis – a multidisciplinary approach

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Introduction: Increased survival rates raise prospects of pregnancy in CF. However, additional demands are potentially hazardous, with further compromise of respiratory function (esp mod–severe disease, FEV1 < 60% pred) or with pulmonary HTN. Prematurity ranging from 5–45% are reported.
Aims: 2 CF patients completed successful pregnancies. Management was based on recommended guidelines, emphasis on optimising respiratory function, monitoring (maternal nutrition, weight gain, screening for gestational diabetes) and alerting anaesthetics in advance of elective C-sections.
Cases: 25 year-old patient A presented at 14 wks, FEV1 1.5L. This fell to 1.19L at 6 mo, rising to 1.8L at term. Main complication was decreased weight, 49.2 kg (ideal 57.0 kg) so nutritional support was maximized, via PEG tube. Exacerbations were treated in standard fashion. An elective C-section was performed at 32 weeks due to repeated exacerbations, delivering a female infant, 1.79 kg, who required 5 day NICU care but no ventilatory support.
19 year-old patient B presented at 8 weeks, FEV1 1.1L rising to 1.59L at term. Main complication was repeated exacerbations treated with standard antibiotics. A multidisciplinary decision was made for elective C-section at 35 weeks, delivering a female infant 2.75 kg who required no special care. Both patients were consulted by anaesthesia pre-delivery, received spinal anaesthesia and antenatal steroids. Neither child has CF.
Conclusions: Optimisation of pulmonary function prior to conception provides the best chances of success. These successful pregnancies demonstrated importance of the multidisciplinary (physicians, obstetricians, anaesthetists, physiotherapists, dieticians and social workers) management plan necessary for success.

415* Increased segregation in an adult Cystic Fibrosis centre: the impact on patients' feelings and behavior

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Introduction: Segregation of patients with different strains of Pseudomonas Aeruginosa is recommended [1] and has taken place in Manchester Adult Cystic Fibrosis Centre (MACFC). There is little information available about the impact of segregation upon adult CF patients' emotional reactions and behaviors, although many have longstanding friendships with peers with CF. Questionnaires were administered to patients at MACFC to ascertain patients' reactions following substantial changes to the CF ward (e.g. closure of the communal dayroom, no mixing allowed on the ward) and further segregation in out-patient clinics.
Methods: A self-completed survey questionnaire was distributed to 100 consecutive eligible patients attending the CF ward and clinic 1 year after the introduction of new segregation measures.
Results: 100 completed questionnaires were collected (43% of total eligible patients), 57% male, mean age 28.5. Following segregation, most felt that CF patients with different infections should be segregated (69%). There were positive reactions to segregation – 77% felt safe, 43% pleased, and 41% relieved. 82% were not worried and 78% not angry. There were also negative feelings, with 36% not pleased, 37% not relieved, 50% felt isolated and a minority felt angry (12%) or worried (9%). 13% stated that they had avoided hospital admission because of segregation on the ward and 14% reported that they had made their hospital stay shorter for the same reason. 17% of all patients surveyed said that they came into contact with people with CF outside hospital.
Conclusions: There are positive and negative emotional reactions to segregation in adults with CF. Even those who believe it should take place may feel negative or have mixed emotions. Some patients' health care may be affected by segregation.

References

[1] CF Trust 2004.

416 Segregation in Manchester Adult Cystic Fibrosis Centre (MACFC): patients' views on what they need

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Introduction: CF patients have experienced changes in the organisation of CF wards and clinics due to new cross infection control measures [1]. Patients' concerns about segregation need to be addressed. Patients at MACFC were surveyed to establish their remaining educational needs and suggestions for what might help in adjusting to segregation on a CF ward.
Method: A structured self-completed questionnaire was distributed to 100 consecutive adult CF in- and outpatients with Pseudomonas aeruginosa infection, 1 year after new segregation measures and relevant educational input took place in the unit.
Results: 31% of respondents reported not knowing their own infection status. A further 3% incorrectly reported their status despite the fact that 63% had been admitted to the segregated CF ward that year. 36% of all respondents felt they needed more information about cross infection and explanations for segregation. Of these, 42% felt a written leaflet would be most useful, while 28% preferred to receive information via letters, and 22% in face-to-face discussions. 67% of respondents had suggestions for what might help deal with the effects of segregation. Most common requests were for: recreational activities to help pass the time (especially cable TV/game consoles/dvds), ensuite bathrooms, computer and internet access in each room, and access to kitchen facilities. 4 respondents reported they should be able to continue to mix on the ward at their own discretion.
Conclusion: Many adult CF patients have unmet needs for information about cross infection and the reasons behind segregation, but different modalities are preferred for the delivery of such information. Adults attending a large CF centre have many practical suggestions for things that may serve to ameliorate negative effects of segregation.

References

[1] CF Trust 2004.