

323 Transplantation and changes in importance of social support

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Aim: As part of a larger study on preparation for transplantation (tx) we report on changes in social support before and after tx.

Method: 59 tx CF patients from 2 tx centers (mean age = 32; 24 females; mean days on waiting list = 348; mean time since tx = 4.7 years) rated the importance of 18 sources of social support. Patients completed the scale retrospectively referring to the situation before tx and at present. Demographic variables were living situation, work/study status and partner status.

Results: 26 vs 19 patients (before vs after tx) lived with their parents. 31 vs 35 patients were in a long-term relationship/marriage; 3/17 patients got divorced after tx; 23 vs 25 patients were in study/work; unemployment status because of health decreased from 35 to 27. Correlation analysis showed that younger patients benefited more from (grand)parental support than older patients for whom partner support was more important. Days on waiting list was related to the importance of support from other CF patients. Paired t-test analysis showed a significant decrease in importance of support from CF team members before vs. after tx, even though in both centers the teams take care of CF and CF tx patients. Importance of support from outside the hospital also significantly decreased (mother, father, grandparents, CF patients and (marginally) partner).

Conclusions: The importance of sources of social support changes significantly after tx. This can be explained by the improvement in health and renewed independence. Frustration or disillusion with parents or partners, observed in clinical practice, may be the result of these changes. This issue should be addressed whilst preparing for tx and after tx.

325 Acupuncture in CF: is there a point?

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Pain, particularly headaches, chest and back pain (chronic and related to acute exacerbations) is common in older CF patients, and can be more severe in the last few months of life. Also, acute pain during an exacerbation can decrease physiotherapy tolerance, leading to sputum retention and diminished levels of fitness. Acupuncture is one treatment modality that can help alleviate pain and is commonly used in palliative care.

To gain an insight into its value in CF, it was offered to 12 adults undergoing inpatient IV therapy: all had neck or back pain interfering with chest physiotherapy. Three declined acupuncture (fear of needles); the remaining 9 (5 female) were treated with an individualised range of acupuncture points relating to their area of pain. Pain levels were recorded pre and post treatment on a plain 10 cm line VAS. One patient underwent a series of treatments, whilst all others had a single treatment.

There was an improvement in pain score with treatment (VAS pre treatment: mean 4.41 [range 8.2 to 2.0] versus post treatment: 2.95 [6.0 to 0.3], $p < 0.001$). One patient reported no change in their pain level but all patients reported an increased feeling of wellbeing post treatment. No adverse reactions to acupuncture were experienced. The patient who received a series of treatments reported subsequent drops in pain levels from a score of 8.2 cms pre initial treatment to 5.5 cms post treatment after 3 episodes of acupuncture. Pre VAS scores on the second and third treatment showed the pain level to remain lower than the initial score.

Acupuncture is a valuable adjunct treatment option for acute pain in CF patients. A further study is underway to determine if these observed changes in subjective pain will have a positive effect on adherence to treatment in this patient group.

324* Eating disorder symptomatology in cystic fibrosis before and after transplant: A case presentation

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Clinicians working with cystic fibrosis (CF) have long recognized there may be aberrations associated with eating/attitudes in their patients. CF patients are exposed to predisposing conditions towards the development of eating disorders (ED), or disordered eating (DE). In Phase I of the research project to investigate the association between CF and ED, several standardized ED instruments were administered to adults and children with CF. Results indicated that patients with CF exhibited symptoms associated with ED/DE that may impede maintenance of the disease or compromise health status. Patients with CF exhibited a variety of eating patterns and attitudes which ranged from “normal” through to ED as well as another class of ED symptoms specific to CF patients. The study also found the assessment instruments presented with distinctly different factor structures when utilized with non-ED populations questioning their construct validity in a CF population. Phase II of the project is currently underway to develop a CF specific ED screening tool. Individuals with CF are being invited to discuss their struggles with weight and body image. One adult participant in both Phase I and II discussed at length her difficulties with body image, weight and nutritional status pre and post transplant. The complexity of her issues support the need for assessment in this area and a valid instrument for screening ED and CF related ED symptoms in patients with CF. Through a case study format, the details of the woman’s struggles and successes will be presented in accordance with her responses to the standardized ED instruments and the piloted CFED questionnaire.

326 Referrals to a new adult CF psychology service

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Although little has been published on the prevalence and nature of psychological problems in adult CF, concerns have been raised about the ability of standard screening measures to detect the full range of psychological problems in adults with CF. To look at this further, we compared the first 6 months of referrals to a clinical psychologist at our large adult CF centre with published data.

Referrals were recorded on a database adapted from the paediatric service altered to reflect the range of problems seen in adult patients.

22 patients (6 [27%] inpatients) were referred (median age 23 years [interquartile range = 5], 12 male). These figures were similar to the remaining CF clinic population. Reasons for referral are shown in the table.

Other reasons included pain management, relationship issues, impact of mental health problems on CF care, and decision making around treatment. Two patients declined to see the psychologist. Of the 20 seen, all but 2 identified similar concerns to those raised by the referrer.

Our findings are consistent with previous work showing that anxiety and low mood are commonly reported psychological problems in adults with CF, and support the contention that the diverse nature of psychological difficulties seen in CF means that standard measures may be less effective. Further practice based studies are needed alongside larger scale screening to determine whether similar results would be seen in the wider adult CF population.

Referral reason	Anxiety/ panic	Low mood/ depression	Phobia/ procedural anxiety	Treatment adherence	Eating/ nutrition	Other
Number (%)	4 (18%)	7 (32%)	3 (14%)	2 (9%)	2 (9%)	4 (18%)