

**325 Development and evaluation of an internet-based psychological intervention for parents of children with cystic fibrosis**

L. Goldbeck<sup>1</sup>, C. Knaevelsrud<sup>2</sup>, C. Lehmann<sup>3</sup>, C. Weiss<sup>3</sup>, A. Fidika<sup>1</sup>, M. Herle<sup>1</sup>.  
<sup>1</sup>University Ulm Medical Centre, Child and Adolescent Psychiatry/Psychotherapy, Ulm, Germany; <sup>2</sup>Free University Berlin, Clinical Psychology, Berlin, Germany; <sup>3</sup>Charité – University Hospital, Christiane-Herzog-Centre, Berlin, Germany

**Objectives:** Many parents of patients with CF have high levels of anxiety and/or depression that might interfere with adherence to treatment regimes. However, there is a lack of evidence-based psychological interventions for this target group. Internet-based psychotherapy can reach out for parents who have limited access to psychosocial services. We developed an internet-based supportive intervention and evaluated its feasibility, acceptance and efficacy in a pilot study.

**Methods:** A short cognitive-behavioral intervention focussing on disease-related aspects was developed by a clinical expert panel and then realized on a study website. We conducted a single-group intervention study with pre-post-3 months follow-up design. All participants received a comprehensive psychological baseline assessment. Treatment for those with elevated symptoms of anxiety (HADS score >7) was performed as standardized writing therapy by carefully trained and supervised psychotherapists. Primary endpoint was the reduction of anxious symptoms, secondary endpoints were the reduction of depressive symptoms, improvement of parental quality of life and of disease-related coping skills. Additionally, feasibility and acceptance of the intervention were evaluated.

**Results:** Thirty-one parents started treatment. Most of them were female, had much experience with the internet and had never received psychological counselling in the CF-centre. At baseline, HADS anxiety scores were between 8 and 17 (M=11.6; SD=2.8), average CES-D score was 16.7 (SD=6.6).

**Conclusion:** So far, the intervention is well accepted and feasible. Data on the efficacy of the intervention program will be due for the presentation.

**326 Parent's satisfaction with an internet-based supportive intervention for parents of children with cystic fibrosis**

A. Fidika<sup>1</sup>, M. Herle<sup>1</sup>, C. Knaevelsrud<sup>2</sup>, C. Lehmann<sup>3</sup>, C. Weiss<sup>3</sup>, L. Goldbeck<sup>1</sup>.  
<sup>1</sup>University Hospital Ulm, Department of Child and Adolescent Psychiatry/Psyc, Ulm, Germany; <sup>2</sup>Free University Berlin, Department of Clinical Psychology and Psychotherapy, Berlin, Germany; <sup>3</sup>Humboldt University, Charité, Department of Paediatric Pulmonology and Immunology, Berlin, Germany

**Objectives:** A pilot study of an internet-based cognitive behavioral intervention program for severely distressed parental caregivers of minors with CF has been conducted. Besides the evaluation of the efficacy, which is reported separately, it was aimed to describe the parent's satisfaction and acceptance of the treatment program and its components.

**Methods:** Altogether 31 parents participated in the pilot study. The program consists of nine writing assignments related to three treatment components: coping with fear of disease progression, sharing responsibility for the CF-treatment, and providing self-care. After completion of each treatment component as well as at the end of the intervention program, parent's satisfaction was assessed via online-questionnaires. Additionally, parents were encouraged to make also critical comments on the assignments.

**Conclusion:** So far, 19 parental caregivers completed the program and all satisfaction-assessments. The available data seems very promising. The average parent's satisfaction was in between 3.5 and 4 on a scale ranging from 0 (very unsatisfied) to 5 (very satisfied) for the respective treatment components. The acceptance of the entire treatment program (design, presentation, and content) was also satisfactory. All parents stated, they would recommend it to friends, who find themselves in a similar situation. Associations between satisfaction scores and treatment efficacy will be evaluated when data of all participants are available. This study was supported by a financial grant from Mukoviszidose Institut gGmbH, Bonn, the research and development arm of the German Cystic Fibrosis Association Mukoviszidose e.V.

**327 What parents want from parents' evenings**

H.B. Gormley<sup>1</sup>, A. Duff<sup>2,3</sup>, K.G. Brownlee<sup>3</sup>, C. Hearnshaw<sup>4</sup>. <sup>1</sup>University of Leeds, Institute of Health Sciences, School of Medicine, Leeds, United Kingdom; <sup>2</sup>Leeds Teaching Hospitals NHS Trust, Department of Clinical and Health Psychology, Leeds, United Kingdom; <sup>3</sup>Leeds Teaching Hospitals NHS Trust, Regional Paediatric CF Unit, Leeds, United Kingdom; <sup>4</sup>University of Leeds, School of Medicine, Leeds, United Kingdom

**Objectives:** Ongoing education and support for parents of children/teenagers with CF is required and parental engagement in event-design is key. Often this is only secured from parents who previously participated. We evaluated our 2012 parental educational event, taking feedback from those who did and did not attend. We aimed to increase participation and attendance, and tailor the format of future events to parent preferences.

**Methods:** Parents (n=50; 25 attendees) completed semi-structured telephone interviews that were interpreted using frequency data and content analysis. There were no differences in health status (FEV<sub>1</sub>, FVC, FEF25–75, Wt, Ht and BMI), of the children/adolescents of attendees and non-attendees.

**Conclusion:** All participants were satisfied with topics covered and mode of presentation. The main benefit of the event was reported as contact with parents rather than educational, with many feeling isolated and having little contact with other parents. 64% of non-attendees perceived content to be relevant and 52% wanted to attend but experienced practical difficulties. Other non-attendees reported actively limiting participation in CF-related education as part of their coping style. Practically, parents (n=46), were mostly satisfied with the hospital location and week-day (n=42). 58% were dissatisfied with a 6:00pm start-time. Recommendations for future events included

- i. starting after 6:30pm
- ii. small-group sessions arranged by topic not the child's developmental stage
- iii. more events and a parent support-group
- iv. collating questions in advance and a 'read and answer' session
- v. increased parental interaction at, and involvement in planning, the event.

**328 Exploring parents' concerns about transition from paediatric to adult cystic fibrosis (CF) services**

H. Oxley<sup>1</sup>, S. Woodhead<sup>1</sup>, J. Biesty<sup>1</sup>, J. Fauset-Jones<sup>2</sup>, S. Trenchard<sup>2</sup>. <sup>1</sup>Manchester Adult Cystic Fibrosis Centre, Manchester, United Kingdom; <sup>2</sup>Royal Manchester Children's Hospital, Cystic Fibrosis Centre, Manchester, United Kingdom

**Objective:** To identify transition concerns of parents of adolescents with CF, prior to transfer to a UK adult CF centre. Most transition work aims to support the adolescent with CF through the move from paediatric to adult services. However, the transition process also impacts on parents. The literature suggests a range of potential transition concerns for parents that may need to be addressed by services.

**Methods:** Survey questions about parents' concerns regarding transition, based on the literature, were devised by a working group of staff from paediatric & adult CF centres. A postal survey was sent to 106 parents with an adolescent with CF aged 13–17 attending paediatric care. Parents were asked to rate their level of concern about several transition issues relating to both the transfer between services, and to adulthood with CF in general. Parents were asked if they would like more information about their areas of concern. The feasibility of carrying out a parents' transition information evening was explored by asking parents if they would attend such an event.

**Conclusion:** 43 surveys were returned. Results indicated parents had several concerns relating to the transfer of CF care, particularly: their adolescent being able to manage their CF independently, exposure to infection, and adult inpatient admissions. Life expectancy, their adolescent leaving home and potential medical problems were parents' greatest concerns about the transition to adulthood with CF. All parents expressed an interest in attending a parents' transition event. Parents of adolescents with CF have a range of transition related concerns and are interested in receiving more information about these.