313 Effect of CFfone on knowledge of disease management, psychological well-being, and health-related quality of life in adolescents and young adults with CF

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Objective: This study evaluated the efficacy of an online intervention, CFfone, to improve knowledge of disease management, perceived support, psychological well-being, and HRQoL.
Methods: The current study is a randomized controlled trial at 6 CF Centers across the USA. Participants were randomly assigned to either:
1. CFfone or
2. an educational website on CF.

Participants completed the following measures at baseline and post assessment:
1. Knowledge of Disease Management (General Health, Lung Health, Nutrition, and Treatment),
2. the Hospital Anxiety and Depression Scale (HADS; anxiety and depression), and
3. the Cystic Fibrosis Questionnaire – Revised (CFQ-R; Treatment Burden, Social Functioning, and Respiratory Symptoms).

Results: Preliminary results compared Baseline and post-visit data in participants in the CFfone condition (n = 7, M = 14.80 years, SD = 2.75). Overall Knowledge improved ($\Delta M = 22.45$) on scales measuring General Health ($\Delta M = 26.76$), Lung Health ($\Delta M = 17.85$), Nutrition ($\Delta M = 22.90$), and Treatments ($\Delta M = 23.37$). Anxiety symptoms decreased ($\Delta M = 1.86$) more than depressive symptoms ($\Delta M = 0.15$). Improvements on the CFQ-R were also found: in Treatment Burden ($\Delta M = 4.76$), Social Functioning ($\Delta M = 19.62$), and Respiratory Symptoms ($\Delta M = 20.24$).
Conclusions: Preliminary results indicate that CFfone may be a promising intervention, with benefits across multiple domains including knowledge, psychological well-being, and HRQoL. Future directions include examining the long-term effects of the intervention and comparing the outcomes of those in the CFfone vs. control group.

314 The association of parent–child processes and adherence in children with cystic fibrosis

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Background: Children with cystic fibrosis (CF) must adhere to prescribed treatments for good health. Parents are responsible for administering these treatments and we don't know the stress this puts on the parent–child relationship.
Objectives: To explore if parent–child processes in stories about medical procedures using a standard play procedure are associated with adherence.
Methods: A subsample from the Home Intravenous Antibiotic Study of 10 boys and 10 girls aged between 3 and 9 years completed an established standardised play procedure, the MacArthur Story Stem Battery (MSSB). The stems "Doctor's Test" about having a blood test in clinic, "Day Out" about CF care disrupting a planned excursion and "New medicine" about a child beginning a new medicine were designed specifically for children with CF. Coherence (story telling performance), intentionality (interpersonal sensitivity) and avoidance (removal of difficult emotions) are rated on 12 point scales where 1 = absence of process and 12 = very marked process in observed play. Adherence was reported over a 2 week period, and scored by a researcher blind to MSSB scores into a 7 point scale where 0 = total adherence and 6 = total refusal to a prescribed treatment.
Results: The MSSB is a feasible and acceptable assessment for children with CF. Spearman's rank correlations showed high coherence correlates with low refusal ($r = -0.72$, $p < 0.001$), high intentionality with low refusal ($r = -0.50$, $p < 0.05$) and high avoidance with high refusal ($r = 0.51$, $p < 0.05$).
Conclusions: The robust correlations suggest the MSSB's use to screen children at risk of poor adherence in order to provide early intervention for these families.

315 Shifting responsibilities for self-management of cystic fibrosis: getting the balance right

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Background: Cystic fibrosis (CF) is a life-shortening illness that places complex demands on young adults and their parents as responsibilities for self-management shift between them. Little is known about the responsibilities young adults and parents assume toward self-management of CF, and how health professionals take account of changing roles.
Aims or objectives: To explore the roles and responsibilities that young adults and parents assume toward self-management of CF care.
Methods: Ethnographic design using in-depth interviews with a purposive sample of 13 young people with CF (aged 13–22 yrs) and their parents. Interviews were conducted in participants' homes. Data were analysed using the constant comparative method to explore developing themes.
Results: Young adults assumed increasing responsibility for 'controlling CF disease', which was a means to achieving broader goals of emotional and social happiness in life. Parents' roles in supporting their children were mainly concerned with emotional management. Communication patterns between parent and child were key to relatively smooth or problematic shifts in responsibilities. Accounts indicated that health professionals mostly worked within 'disease management' with little regard for the day to day experiences of managing CF in the home setting.
Conclusions and implications: This study broadens understanding of self-management of CF care by highlighting a need to go beyond medical management to include emotional, social and role management. Getting this balance right would be important to developing self-management programmes for cystic fibrosis.

316 Factors that increase depression in adults with cystic fibrosis

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Introduction: Life expectancy in CF is improving with a UK median life expectancy of 41.4 yrs (2010). However, higher rates of anxiety and depression have been associated with increasing age.
Aim: To evaluate the prevalence of depression and anxiety in adults with CF attending the Royal Brompton Hospital and to identify factors associated with both.
Methods: Over a one year period patients completed the Hospital Anxiety and Depression Scale (HADS) while attending outpatients. Additional demographic data were collected including level of education, employment status and measurements of health (e.g. FEV_1, BMI, presence of CFRD, Portacath, pneumothorax or haemoptysis).
Results: Participants n = 326, age – mean 30.9 yrs (SD 10.26), males n = 171 (48%), FEV_1 – mean 58% (SD 24.3). HADS: Total population – anxiety score mean 6.42 (SD 4.35), depression score – mean 3.51 (SD 3.24), total number with depression n = 41 (13%), total number with anxiety n = 127 (35%). Factors included in regression analyses included measurements of health, employment and education. Regression analyses show a significant association between increasing age ($p < 0.005$), decreasing health status ($p < 0.001$) and employment status ($p < 0.001$) with depression. Anxiety with female gender ($p < 0.005$) was also significant.
Conclusions: This large, single centre study shows a suprisingly low incidence of depression with a higher incidence of anxiety, particularly in females. However, overall scores for both are low – anxiety (6.42) and depression (3.51) (mild range 8–10). Factors that have a significant negative impact on depression are age, FEV_1 and employment status.