Adherence to nebulised therapies does not improve during school holidays for children with CF

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Introduction: Treatment regimens for families of children with CF are considerable particularly when nebulised therapies for chronic Pseudomonas (PsA) airway infection are prescribed. Adherence to these treatments depends on a variety of factors. Previously we reported children to be more adherent in evenings compared to mornings (ICF2009), suggesting a link to time pressure. In this study we hypothesised that adherence would be better in school holidays when time pressures may be less.

Method: Patients were enrolled from 2 regional paediatric CF centres. Data for a full scholastic year were downloaded openly from a breath-activated data logging nebuliser (I-Neb™), from patients who had been on anti-PsA therapy for >12 months. Adherence (% of doses taken ÷ expected number) was calculated during termtime, holidays, weekends and weekdays.

Results: 22 patients (14 male, median [range] age 13.9 [11.1−16.8] yrs) participated (regimen ranging from once to 3 times daily). Adherence during termtime was significantly better than holidays (67% (±28 SD) vs 62% (±30 SD), p < 0.001). Weekday adherence was better than weekend adherence in termtime but not in holidays. Adherence during specific holidays was no different (Christmas 56%±3.8, Easter 62%±3.4, Summer 60%±3.2, Collective half term 63%±3.2).

Conclusion: These data suggest that whilst overall adherence to inhaled therapies is reasonable, it is reduced during holiday periods. This suggests the need for families to have not only time but also structure in their daily routine to maintain long term adherence. It is important for teams to appreciate these factors to support families with challenging long term therapies.

Difficulties with eating during the school day

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Background: In an attempt to tackle childhood obesity the UK Govt introduced legislation to regulate the nutrient standards of school meals in 2009. These aim to reduce salt, fat and sugar whilst increasing fruit, veg and other nutrients in school meals. Children with CF report increased difficulties in obtaining an appropriate dietary intake.

Findings: Information was available on 9 children at Primary school (6.3–10 years age range) and 10 at secondary school (12.4–16.3 years age range). 32% took packed lunches, 31% had school dinners and 37% had a combination of both. Of these 86% were unhappy with the current school meals. Both groups complained about small portion sizes and they felt hungry. Children who chose to take a packed lunch to avoid this reported being told off for “unhealthy items” in their lunchbox. When high calorie snacks were allowed they were frequently not taken as the children disliked appearing different to their peers. Children complained of long lunches, not enough time to eat and missed on average 1 meal a week (range 1–3) due to this. They also complained about food running out. All reported eating on the way home. These items were usually high fat high calorie foods.

Conclusion: Children with CF find it increasingly difficult to access high calorie school lunches. This may be partly due to changes in legislation well as short lunch breaks. These difficulties will be exacerbated if regulations are imposed on packed lunches.

The prevalence of ‘risky behaviour’ in adults with cystic fibrosis

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Background: ‘Risky behaviour’ describes participation in certain forms of behaviour which pose a risk to the participating person or persons eg. smoking, illicit drugs, excess alcohol and unprotected sexual intercourse. As CF is a multisystem disease requiring multiple medications, this behaviour has the potential to cause additional risks to physical and psychosocial health. This study was performed to assess the prevalence of such behaviour.

Methods: Prospective, questionnaire-based, study. All patients (n = 599) attending our adult cystic fibrosis unit were sent postal questionnaires to complete anonymously.

Results: 182 patients responded (55% female; 53% age >30 y). 83% (n = 151) of respondents drink alcohol (13% above daily recommended guidelines). 46% (n = 84) have tried smoking (3% currently smoke >6 cigarettes/day (range 1–20)), 35% (n = 64) have tried and (3% still use) illicit drugs [cannabis (88%), cocaine (39%), ecstasy (30%), glue (6%) and heroin (2%)]. 85% (n = 154) are sexually active; of these, 55% have had >4 partners and 60% use contraception. Compared with the general UK adult population, less CF patients drink above recommended guidelines (23 vs 13%; p < 0.001), less smoke regularly (21 vs 3%; p < 0.001), less have tried illicit drugs (37 vs 35%; p < 0.001), less are sexually active (97 vs 85%; p < 0.001) but the same proportion use contraception (61 vs 60%; p = 0.8).

Conclusion: Participation in risky behaviour at our unit was modest but currently less than the national average. With CF life expectancy improving this could increase – education and early recognition are required so that prevention can be promoted and appropriate interventions can be introduced.