Patient evaluation of WebEx (Cisco) ‘online chat rooms’ on tube feeding in adult cystic fibrosis

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Introduction: There are no real-time online chat rooms established for peer support and education on tube feeding at Nottingham Adult Cystic Fibrosis (CF) Unit, even though traditional focus groups are not possible because of the strict protocol on patient segregation.

Aim: To evaluate Webex conferencing for hosting ‘online chat rooms’.

Method: A retrospective questionnaire was completed by e-mail or face to face with 23 home tube feeding patients (mean age 29) and the CF Dietitian, as part of the qualitative real-time study on exploring patient experiences of tube feeding.

Results: 15 patients were evaluated; 100% wanted to re-use the chat room; 93% stated it was the first time they ‘chatted’ online with others about tube feeding; 93% preferred the Dietitian facilitating, with 80% not wanting to lead future chat rooms; webcams (13%) and telephone (7%) were stated as additional functions for improvement and 3–5 patients was the optimal range per chat room.

Pros: “The chat room was easy to use and led to a pretty uninhibited exchange of views. I can’t think of a better way for a group of people with CF to discuss issues . . .” “. . . it gave me a chance to talk to people in the same situation as myself, you don’t feel so alone knowing someone else is going through the same problems etc.” and “enjoyed it, good to hear others’ opinions. Helped me approach tube feeding with my girlfriend.”

Cons: “Being slow at typing held up the conversation” and “When several people were typing comments at the same time made it hard to keep things in sync.”

Conclusion: Synchronous OFGs can be dynamic, fun, enjoyable and offer invaluable peer support amongst patients who are faced with CF social isolation.

Promoting weight gain with olanzapine in underweight adults with cystic fibrosis

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Background: Optimising nutritional status can be difficult for people with Cystic Fibrosis (CF). The antipsychotic olanzapine is associated with weight gain, leading to its use in promoting weight gain in patients with anorexia nervosa. This case series describes the use of olanzapine as an appetite stimulant in CF patients.

Methods: In an adult CF unit, patients who had poor nutritional status despite intensive management by a multidisciplinary specialist CF team were prescribed olanzapine 2.5–5 mg daily. Clinical measurements, including weight, height and body mass index (BMI), were recorded during the course of olanzapine therapy. Adverse events were recorded.

Results: Thirty one patients were treated with 39 courses of olanzapine. Median age was 22 years (16–43 yr), 17 female. Median BMI at initiation was 16.9 kg/m² (range 14.8–20.8). Twelve patients took enteral feeds and all patients took oral sip feeds during treatment.

The median duration of treatment was 10 months (range 2–56). Nineteen patients completed at least 12 months treatment with olanzapine. After 12 months treatment, the mean±SD change in BMI was an increase of 1.8±1.5 kg/m² (p=0.001, n=19) and the mean±SD change in weight was an increase of 5.1±4.7 kg (p=0.038, n=19). Fifteen patients discontinued treatment within the first 12 months, 7 of whom failed to gain weight. Side effects included drowsiness, elevation of liver function tests, loss of taste, and restless legs.

Conclusions: Olanzapine can be useful in promoting weight gain in underweight CF patients in addition to standard methods of optimising nutrition.

Change in fat soluble vitamin concentrations following the introduction of AquADEX in adults with cystic fibrosis

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Poor absorption of fat soluble vitamin is common in patients with Cystic Fibrosis (CF) and pancreatic insufficiency. The aim of this study was to evaluate the impact of introducing a new CF multivitamin preparation, AquADEX (Yasoo Health), on levels of vitamins A, D, E and K in adults with CF previously prescribed ADEX (Axcan Pharma). The vitamin content of 2 ADEX vs 2 AquADEX are as follows: Vitamin A ~ 18,000iu vs 36,334iu; Vitamin D3 ~ 800iu vs 1600iu; Vitamin E ~ 300iu vs 300iu and Vitamin K ~ 300mcg vs 1400mcg. A retrospective notes review was performed to compare levels of vitamins A, E and D, parathyroid hormone (PTH) and prothrombin time (PT; surrogate marker of vitamin K levels) before and after introducing AquADEX. Measurements were made at annual review (which occurred at the same time of year). Paired data were available for 64 patients (total clinic n=249), mean(SD) age 27.1(0.8) years, FEV1 63.6(22.1)%s, BMI 22(2.7)kg/m². The time between first prescription of AquADEX and vitamin level measurement was 263(112) days. Mean(SD) concentrations of analytes before and after changing to AquADEX [normal range in square brackets] were: vitamin A: 1.54(0.60) vs 1.63(0.57)mmol/l; p=0.20 [1.05–2.80mmol/l]; 25-hydroxyvitamin D: 16.97(7.84) vs 21.51(10.22)ng/ml, p = 0.0001 [-20ng/ml]; PTH: 52.98(31.32) vs 43.00(21.53)ng/l, p = 0.03 [14–72 ng/l]; vitamin E: 25.86(11.20) vs 22.79(8.77)mmol/l, p = 0.019 [11.5–35.0mmol/l]; PT: 12.5(1.22) vs 12.73(1.03) s, p = 0.087 [10.1–15.3 s].

In conclusion, the introduction of AquADEX has led to a significant improvement in vitamin D levels but a reduction in vitamin E levels in CF adults attending our centre.

Fat-soluble vitamins (A and E) status in children with cystic fibrosis

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Introduction: Pancreatic insufficiency (PI) in cystic fibrosis (CF) is the main cause of impaired digestion and absorption, foremost fats and proteins, and fat-soluble vitamins as a consequence.

Aim: Investigate the status of fat-soluble vitamins (A and E) in children with CF, and efficiency of these vitamins standard oral supplementation.

Materials and Methods: First group – 11 new-born PI CF patients, revealed as a result of neonatal screening program in Moscow. Concentrations of serum vitamins A and E were investigated at the time of diagnosis, then after one month of being on pancreatic enzymes (Creon) only and after another month of combined enzymes and vitamins treatment (vitamin A ~ 3000 ME and E ~ 25 ME per day). Second group – 14 CF children from Moscow (age 7−11 yrs), regularly receiving fat-soluble vitamins in standard doses (vitamins A ~ 3000 ME and E ~ 200 ME per day). Serum levels of retinol and tocopherol were determined by high-performance liquid chromatography.

Results: In the fist group a concentration of (M±m) of vitamins A and E in blood was 12.3±2.2 ng/dl and 0.52±0.12 mg/dl accordingly. Level of retinol on enzyme therapy raised on 36.3% (p < 0.051) and after adding vitamin A increased on 84.1% (p < 0.03). Levels of serum tocopherol did not change significantly despite of adding pancreatic enzymes and then vitamin E. In half of children from the second group we revealed insufficiency of vitamin A. Deficit of vitamin E was even more marked – up to 86% of patients had low concentration of vitamin E.