

POSTER PRESENTATION

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How a motivation programme can affect complex treatment compliance in a rare disease? Results of a questionnaire-based, self-reported study to evaluate “Life Club CF”, a programme intended for patients with cystic fibrosis

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Background

“Life Club CF” is a motivation programme for patients with cystic fibrosis (CF) in Poland, initiated and coordinated by “MATIO” Foundation (Krakow, Poland). Participants collect points for regular specialist outpatient follow-up, adequate nutrition, conducting physical exercise, regular drug intake and reduction in the number of exacerbations. These factors play a major role in complex treatment of CF. Patients may exchange collected points for rewards, such as toys, digital cameras, computers and others. The program was evaluated in a questionnaire-based study.

Aim

The programme was created to increase treatment compliance through promoting responsible activities among patients with CF and encouraging regular, multidisciplinary outpatient follow-up. Questionnaire-based study was conducted to evaluate how the programme accomplishes these objectives.

Methods

A questionnaire consisting of two parts was used: general evaluation (2 questions) and activity before and after having signed up in the programme (7 single-choice questions: rhDNase intake, body mass control,

physical activity and attending outpatient consultations - CF physician/pulmonary specialist, physiotherapist, dietician and psychologist). It was completed either by patients or parents/caregivers. Chi-square and Fisher-Freeman-Halton tests in StatsDirect software package were used to analyse the contingency tables of answers for statistical significance.

Results

89 questionnaires were returned (53 women and 36 men). The studied group consisted mostly of children with CF; 86.5% were aged 18 and less (mean age: 13.7 +/- 5.6). Significant differences in frequency of dietician (once a year: 9% vs. 21.3% / once in 6 months: 31.5% vs. 48.3%; $p=0.0009$), physiotherapist (once in 6 months: 19.1% vs. 20.2% / once in 3 months and more often: 21.3% vs. 39.3%; $p=0.025$) and psychologist consultations (once a year: 12.4% vs. 16.9% / once in 6 months: 18% vs. 34.8%; $p=0.027$) before and after participating in the programme were detected. Furthermore, significantly more CF patients focus on increasing body weight (57% vs. 75%; $p=0.013$) and regularly perform physical exercise (19% vs. 31%; $p=0.044$). No significant differences in rhDNase intake and frequency of CF clinic consultations were detected.

Conclusion

Motivation programme “Life Club CF” is a novel and effective method in increasing treatment compliance in important aspects of complex CF care, particularly

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multidisciplinary outpatient follow-up, physiotherapy, nutrition and physical activity.

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