#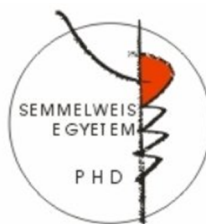 Analysis of the relationship between nutritional status, nutritional habits and quality of life in adult patients with cystic fibrosis

Doctoral Thesis

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1. Introduction

Cystic fibrosis (hereinafter CF) is the most common type of metabolic disease inherited in an autosomal recessive manner. It is a complex multiple organ disease, which can take the form of a chronic respiratory disease, gastrointestinal symptoms, as well as lesions in the pancreas, the liver, the biliary or the reproductive tract. The disorder is characterized by exocrine gland dysfunction, with the result of producing thick, sticky mucus. Phlegm congestion causes obstructive lesions in the relevant organs, especially in the lungs and the pancreas. In 2012 there were 579 patients in the Hungarian CF patient registry, including 261 women and 318 men. The number of adult patients was 248. Owing to their small number, the assessment of adult patients was not possible earlier. Today, however, their increasing number provides the means of monitoring their condition. Since nutritional status plays a significant role in cystic fibrosis progression, dietotherapy must be an essential part of the treatment. Patients with good nutritional status have great chances to preserve and to improve their

health status, which affects their quality of life as well. On the other hand, adverse nutritional status reduces the chances for survival. Disclosing malnutrition and developing an adequate nutritional status therefore play an essential part in an optimal therapeutic treatment.

2. <u>Aims</u>

My aim in carrying out this research is to assess quality of life in adult patients with CF in Hungary for the first time; to collect data about their nutritional status, the factors about nutritional and lifestyle habits, as well as to find correlations between the resulting data and quality of life domains.

3. <u>Materials and Methods</u>

During the research questionnaires were used to assess quality of life in CF patients and their anthropometry parameters were instrumentally assessed, including weight, height, BMI, body fat percentage and muscle percentage.

In the survey 57 patients of both sexes aged over 18 participated. Personal samples were collected several times among outpatients and inpatients in 2013 and 2014.

Inclusion criteria included a diagnosis of cystic fibrosis, age over 18, appropriate cooperation skills, willingness to fill in the questionnaire and to provide anthropometric data, as well as to complete consent form. Inadequate cooperation was considered as ground for exclusion. My research was permitted by Regional, Institutional Research and Ethics Committee of Semmelweis University (91/2013).

Nutritional Status, Lung Function

The patients' nutritional status was assessed by Inbody 170 and Omron bf500 devices based on the principle of bioelectrical impedance, which measure body weight, and thus provide body mass index, body fat percentage and muscle percentage, as well using height value.

Among the patients' lung function data, I focused on the most recently measured FEV_1 value.

Quality of Life

As a means of assessing quality of life, I used the validated Hungarian translation of the disease specific Cystic Fibrosis Questionnaire – Revised (CFQ-R) version for ages 14 and above. (11) (12) This is a questionnaire of 50 questions for 14-year-old or older CF patients, which can be filled in

4

individually and which explains quality of life dividing it into 12 domains: physical functions, emotional functions, social functions, body image, eating disorders, burden of treatment, respiratory and digestive symptoms, roles fulfilment, weight, perception of health, vitality. CFQ–R is a profile type questionnaire, in which the scores range from 0 to 100, where the higher score indicates higher quality of life value. Among the 57 participating patients, 54 filled in the questionnaires, 41 underwent bioelectrical impedance measurements and a total of 38 had a complete data file.

Statistics

For data analysis I used IBM SPSS Statistics 21.0 and Microsoft Office Excel version 2010. Differences were considered statistically significant when p values were $\leq 0,05$. I used Spearman's rank correlation coefficient (r) to express the strength of relationships. Correlation coefficients were defined as weak if r<0, 3, moderate if r=0,3-0,7 and strong if r>0,7. I have used nonparametric tests to measure alterations between continuous variables and also the Mann-Whitney test or Kruskal-Wallis test to analyse the relationship between the categories depending on their number. In order to analyse the relationship between categorical – categorical variables the

chi-square test has been used. I have also applied the nonparametric Mann-Whitney or the Kruskal-Wallis tests to calculate and measure the factors affecting nutritional status.

4. <u>Results</u>

The decimal average age of the patients participating was 28,25 (±8,95); 28,46 (±9,5) of men, and 28,07 (±8,59) of women. The 54 evaluable questionnaires revealed that there were 10 transplant patients among the respondents, evenly divided between men and women. The majority of non-transplant patients were women.

Although the average values of body mass index calculated from measured body weight and height can be found in the normal range, they converge to lower values. The mean values of body fat percentage show that women have a sub-normal range of the mean value. As for muscle percentage, both sexes have their values within the normal range. The FEV1 values of both sexes are low due to the illness.

Nutritional Status

I measured normal values in 52,6% of the sample (25 people), 43,9% (30 people) had low BMI, whereas it was found high in

3,5% of the patients (2 persons). The values of 59,3% of men (16 people) fell into the normal range, 33,3% (9 people) had low BMI, while 7,4% (2 persons) had high BMI. 46,7% of women (14 people) had normal BMI, while low BMI values were found in 53,3% (16 people). High BMI values were not measured in any of the female patients.

Out of 57, 41 people (71,93%) had valid body fat percentage measurement results. According to the body fat percentages data, 35% of men had low values, whereas 55% had normal values. High values were measured in 10% of male patients.

Mean values of body fat percentage of men was 12,09(±5,34) %, while those of women was 20,69(±7,82) %. Both values can be found in the normal range. (Table 1)

52.4% of female patients had low, 38.1% had normal and 9.5% had high body fat percentage values.

Regarding transplantation no significant correlation was found with any of the parameters of nutritional status. However, it can be claimed that FEV1 mean values (72,11%±14,39) in transplant patients were found significantly different from those of non-transplant patients (49,82%±24,62) (p=0,009). As it can be expected, transplant patients had higher values and better lung function.

Quality of Life

Based on the 54 evaluable CFQ-Rs, the highest scores in the quality of life mean values appeared in the eating disorders domain, whereas the lowest ones appeared in the weight domain.

In none of the parameters was found a strong correlation when examining the relationship between the quality of life domains.

BMI moderately correlated with the domains of physical functions (r=0,424; p<0,01), body image (r=0,656; p<0,01), eating disorders (r=0,406; p<0,01), health perception (r=0,435; p<0,01), vitality (r=0,302; p<0,05) and body weight (r=692; p<0,01). Weak correlation was confirmed between BMI and the domains of respiratory symptoms (r=0,271; p<0,05) and roles fulfilment (r=0,285; p<0,05).

Moderate correlation was confirmed between body fat percentage and the domains of emotional functions (r=0,352; p<0,05), body image(r=0,433; p<0,01) and body weight (r=0,406; p<0,05).

Moderate correlation was found between FEV1 and the domains of physical functions (r=0,646; p<0,01), emotional

functions (r=0,301; p<0,05), burden of treatment (r=0,400; p=0,005), health perception (r=0,515; p<0,01), respiratory symptoms (r=0,487; p<0,01), roles fulfilment (r=0,301; p<0,05 and body weight (r=0,417; p<0,05).

Based on the split by gender it can be claimed that there is no significant difference between male and female patients' quality of life, with the exception of the respiratory symptoms domain, where the relevant scores are lower in female CF patients.

Transplantation has an important effect on patients' quality of life. Between the groups of transplant and non-transplant patients I have found significant differences in the domains of physical functions, social functions, burden of treatment, heath perception, respiratory functions and vitality. In each case, transplant patients had higher quality of life values in those domains.

Among the values of transplant patients with CF, in the two domains of body image and body weight the values were lower than those of non-transplant patients. However, in these domains the alterations between the values were not significant.

There were seven domains in which I could find significant differences between the two groups created on the basis of body mass index. Thin patients' quality of life values were significantly lower regarding their physical function (p=0,004), body image (p<0,001), eating disorders (p=0,004) health perception (p=0,018), role fulfilment (p=0,041), vitality (p=0,015) and body weight (p <0,001). Patients with low body mass index had strikingly low values (<40) in the body image and body weight domains.

As far as body fat percentage is concerned, it can be stated that there were significant differences among the three groups in six domains: physical functions (p=0,035), body image (p=0,011), eating disorders (p=0,002) and health perception (p=0,016), roles fulfilment (p=0,048) and body weight (p=0,004). The score related to the body weight domain is exceptionally low (16,67) in the group of patients with low body mass percentage values.

I could not find any significant differences between the groups established by muscle percentage categories in measuring the quality of life values.

Among the groups of patients set up by FEV_1 values, which represent lung function, we calculated significant differences in six domains: physical function (p<0,001), treatment burden

(p=0,029), health perception (p=0,002), respiratory symptoms (p=0,012), roles fulfilment (p=0,034) and body weight (p=0,007).

5. <u>Conclusion</u>

My research is the first disease-specific quality of life assessment among Hungarian adult patients with CF. In Hungary we are the first to study correlations between nutritional status data and quality of life in adult CF patients.

Female patients have worse nutritional status parameters than men. Transplantation did not affect the nutritional status results of the sample.

Transplant patients had decisively better quality of life scores than their non-transplant peers, except for the body image and body weight domains. CF patients with lower BMI had lower quality of life values than their peers.

In general, from the trend of the quality of life scores we can conclude that in spite of the fact that patients did not have eating problems and they did not have to force themselves to eat; still they had difficulties with weight gain. This suggests that the patients are not aware of the characteristics of the diet which is appropriate for them. Therefore, early interventions

should be implemented on the field of diet to improve patients' condition and quality of life.

Quality of life research is necessary to understand the subjective side of the disease. In the future longitudinal studies are supposed to provide a more accurate picture of the quality of life changes and may also be able to explore the effectiveness of the intervention.

6. <u>List of own publications</u>

<u>Original publications in the topic of dissertation:</u>

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3. Tóth T, Mák E, Molnár Sz, Sinka M, Tóth F, Szabolcs I. (2014) Nutrition status of adult patients with cystic fibrosis NEW MEDICINE 18:(2):63-66.

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5. Tóth T. (2012) A sűrítés jelentősége a diétás étkezésben ÉLELMEZÉS 16:(5):26-27.

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6. Mák E, Gaál B, Németh I, Tóth T, Dér A, Karamánné Pakai A, Szabolcs I. (2010) Táplálékallergiás betegek diétázási feltételeinek javítása mesterséges intelligenciával működő tanácsadó szoftver kifejlesztésével BULLETIN OF MEDICAL SCIENCES / ORVOSTUDOMÁNYI ÉRTESÍTŐ 83:(4):256-259.

7. Tóth T, Fehér F, Dusa F, Ruda V, Mák E. (2010) Ketogén diétában alkalmazható ételek érzékszervi bírálata ÚJ DIÉTA: A MAGYAR DIETETIKUSOK LAPJA (2001-) 19:(2):5-7.