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Emotional states and sleep disorders in adolescent and young adult cystic fibrosis patients

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Abstract: The aim of the study was to evaluate level of anxiety, depression and aggression and the sleep quality among Polish adolescent and young adult suffering from cystic fibrosis including the evaluation of their FEV1.

The study involved 70 patients both male and female aged between 14 and 25 and suffering from cystic fibrosis. Anxiety, depression and aggression were evaluated by means of Hospital Anxiety and Depression Scale and the quality of sleep was examined following Athens Insomnia Scale another aspect taken into consideration was patients' FEV1. The data analysis was carried out by means of Chi2, Kolmogorov-Smirnov test, Student's t-test, Fisher-Snedecor test, Pearson correlation coefficient. The level of statistical significance was set at $p < 0.05$.

Anxiety was observed in 27 (38.6%) cases, depression in 17 (24.3%) and aggression in 46 (65.7%) cases. Anxiety ($p = 0.017$) and aggression ($p = 0.004$) were significantly higher among women than among men. 37 (52.8%) patients reported sleep disorders. The findings proved that there is a connection between the quality of sleep and anxiety ($r = 0.631$; $p = 0.000$), depression ($r = 0.621$; $p = 0.000$) and aggression ($r = 0.293$; $p = 0.014$). No significant relationship was found between the quality of sleep and patients' expiratory volume.

Emotional disorders such as anxiety, depression and aggression as well as sleep disorders are commonly reported in patients suffering from cystic fibrosis.

Keywords: cystic fibrosis; sleep; emotional state; adolescents; young adults.

Introduction

Cystic Fibrosis — CF is an incurable disease, which prematurely shortens human life. In Poland the occurrence of the disease is estimated at 1:2300–1:5200, which means that the number of patients who suffer from cystic fibrosis reaches 1500–2000 people and their life expectancy hovers around 22 years [1, 2]. The data is not precise because the Polish register of patients suffering from cystic fibrosis run by the Polish Cystic Fibrosis Society has been suspended for about 3 years.

The fact that the life expectancy of cystic fibrosis patients was prolonged resulted in a change of attitude towards the disease, which is no longer considered to be a problem which affects only children. Current statistical data confirms that the number of adult patients suffering from this chronic disease has been rising over the last few years and 50% of cystic fibrosis patients have a chance to live until the age of 30 [3]. The increase in the survival outcomes is followed by higher responsibility for proper treatment control, enhancing efficiency of medical treatment and minimalizing the negative impact of the disease [4].

Cystic fibrosis leads to negative changes in most body organs, which results in a drastic deterioration of the quality of life [5–9]. This fact is extremely important because the evaluation of quality of life is more and more frequently a part of routine clinical tests and is used by medical teams to develop and introduce the optimal plan of medical care and treatment, to understand patients' emotions and to involve them in the diagnostic and therapeutic process. It has been proved by numerous publications in scientific papers concerning the connection between emotional state and the quality of life of chronic patients including those suffering from cystic fibrosis [10–15]. Due to high risk of emotional disorders in CF patients, it is essential to pay more attention to health aspects different from clinical ones, including being in pain, the quality of sleep and the level of aggressive, anxious and depressive behaviour, because they may have a direct or indirect influence on life satisfaction. The occurrence or exacerbation of the symptoms mentioned above is connected with worse prognosis and worse functioning in many aspects of life, especially for young people [14, 16].

Young people have to take on new roles determined by human development and acquire various new abilities and this process might take place in an undisturbed way only if the proper balance is kept between internal and external factors influencing young people's lives. In the case of cystic fibrosis, which, because of its clinical picture and shortened life expectancy, might evoke negative emotions, it is vital to find out more about psycho-emotional state of patients and make them involved in the treatment process. The evaluation of quality of life including the factors which determine it is the best way to develop and choose the best holistic plan of providing care to the patient [14, 17, 18].

The aim of the research was the evaluation of the incidence of anxiety, depression and aggression as well as the quality of sleep in adolescent and young adult patients including the evaluation of their FEV1.

Material and Methods

The research was carried out in 2016 in the National Tuberculosis and Lung Disease Research Institute in Rabka-Zdrój and among the patients of the Polish Society of Cystic Fibrosis Treatment. As many as 70 cystic fibrosis patients of both sexes aged between 14 and 25 participated in the research.

The Bioethics Committee of Jagiellonian University in Cracow approved of the research (Nr.122.6120.275.2015) and so did the Departmental Head of the Institute in Rabka-Zdrój and Managing Director of the Polish Society of Cystic Fibrosis Treatment. The research was carried out following the appropriate legal rules and bioethical principles of the Declaration of Helsinki.

The participants of the research were divided into 3 age groups: group I (aged 14–16), group II (aged 17–20) and group III (aged 21–25). The groups reflected the division applied currently in Polish education system and indicated the stages of junior high school, high school and university. The groups were created in such a way in order to determine patient's emotional state in a more precise way taking into consideration their present circumstances.

Participation in the research was voluntary and patients' security and protection of their personal data were ensured. Patients were allowed to resign from the study at any stage. The participants of the study had to meet the following requirements: in the case of adolescents aged between 14 and 18 a verbal consent for voluntary participation in the study of one or both of their parents was required; a verbal consent for voluntary participation in the study was required from all adolescents and young adults aged between 14 and 25; clinical diagnosis if cystic fibrosis without other disorders or defects not resulting from the nature of the disease; lack of accompanying diagnosed psycho-emotional disorders; lack of difficult external circumstances (separation, death in patient's family, difficult circumstances).

The research involved a diagnostic poll method: direct or CAWI (Computer-Assisted Web Interview) as well as the analysis of medical records. The evaluation of anxiety, depression and aggression intensity was carried out with the application of HADS (Hospital Anxiety and Depression Scale) [19, 20]. This diagnostic tool consists of 7 questions evaluating anxiety, 7 questions evaluating depression and 2 questions evaluating aggression/irritability. The responses are scored on Likert scale within the range of 0–3 points. Then the scores are added. The results referring to the anxiety and depression scale are interpreted according to the following categories: 0–7 points:

no disorders / low level of anxiety/depression, 8–10 points: borderline, middle level of anxiety/depression, 11–21 points: disorders, high level of anxiety/depression. As far as aggression (irritability) is concerned: 0–2 points: low level of aggression, 3–4 points: middle level of aggression, 5–6 points: high level of aggression.

The quality of sleep was evaluated with the application of AIS (Athens Insomnia Scale) adapted to Polish conditions [21, 22]. The scale consists of 8 questions which allow for evaluation of insomnia symptoms. The responses are scored within the range of 0 to 3 points. The maximum number of points totals 24. The results are interpreted according to 3 score categories: 0–5 points: no disorders, 6–10 points: borderline, 11–24 points: insomnia.

Basic respiratory parameters — FEV1 from the last 2 weeks were obtained from patient's medical records. Pulmonary disease was considered mild for values over 70%, moderate for values between 40% and 70%, and severe for values under 40% [9].

In the findings analysis the values of quality variables were presented by means of absolute values and percentages and the differences within particular groups were examined by Chi^2 test. The values of quantity variables were presented by means of the mean (X) and standard deviation (SD). In order to choose appropriate statistical methods a comparison of the analysed data distribution and a regular distribution was carried out by means of Kolmogorov-Smirnov test.

The relationships between quantity variables within particular groups were examined by means of Student's t-test for independent groups in the case of groups with regular distribution or unifactorial analysis of variance ANOVA, whereas the relationships between particular groups were studied by means of appropriate post-hoc tests. In order to evaluate the strength and direction of a relationship between particular quantity variables r-Pearson correlation coefficient was used for variables with regular distribution. The level of statistical significance was set at $p < 0.05$.

Results

Sociodemographic and clinical data

The research was carried out in a group consisting of 30 (42.9%) women and 40 (57.1%) men. There were 18 (25.7%) people in group I (aged between 14 and 16), 23 (32.9%) people in group II (aged between 17 and 20) and 29 (41.4%) people in group III (aged between 21 and 25). Thirty-seven (52.9%) patients lived in the country, 19 (27.1%) patients in a city with the population below 100,000 and the remaining 14 (20%) patients in a city with the population above 100,000.

The evaluation of weight and height essential for calculating patients' BMI showed that among the cystic fibrosis patients in age group I as many as 10 (14.3%) patients

were underweight — BMI below 18.5. In age group II BMI was lower than 18.5 in the case of 11 (15.7%) patients. Whereas in group III only 4 (5.7%) patients were underweight.

The analysis of FEV1 parameter (Table 1) proved that 10 (14.3%) patients had a severe stage of bronchopulmonary disease, 30 (42.9%) patients were reported to have a moderate stage and further 30 (42.9%) patients were reported to have an early stage of the disease.

Statistical analysis confirmed that there is a significant difference among cystic fibrosis patients in the level of expiratory volume, i.e. the stage of bronchopulmonary disease: $Chi^2 = 11.43$; $p = 0.003$.

There was no correlation between the stage of bronchopulmonary disease and patients' sex ($Chi^2 = 0.856$; $p = 0.652$) or age ($Chi^2 = 2.057$; $p = 0.725$).

Table 1. The relation between patients' expiratory volume (FEV1) and sex and age group.

FEV1 (%)	Sex	n (%)	Age group	n (%)
>70 (n = 30)	F	13 (18.6)	14–16 17–20 21–25	9 (12.9) 11 (15.7) 10 (14.7)
	M	17 (24.3)		
<70 and > 40 (n = 30)	F	14 (20.0)	14–16 17–20 21–25	7 (10.0) 8 (11.4) 15 (21.4)
	M	16 (22.9)		
<40 (n = 10)	F	3 (4.3)	14–16 17–20 21–25	2 (2.9) 4 (5.7) 4 (5.7)
	M	7 (10.0)		
	Total	70 (100)		70 (100)

F = female; M = male; n = number of people

Evaluation of patients' emotional state by means of HADS

Evaluation of selected emotional states (anxiety, depression, aggression) proved the incidence of anxiety in 27 (38.6%) patients, depression in 17 (24.3%) patients and aggression in 46 (65.7%) patients. The sum of the results does not total to 100 because some patients experienced more than one negative emotional state. Detailed results of the analysis of emotional states are presented in Table 2.

The distribution of incidence of the emotional states examined divided according to patients' sex proved to be comparable. Anxiety was experienced by 14 (51.9%) women and 13 (48.1%) men. The feeling of depression appeared in 9 (53%) women and 8 (47%) men, whereas aggression (irritability) was experienced by 23 (50%) patients both women and men.

Table 2. Evaluation of anxiety, depression and aggression incidence in the examined group of patients.

Emotional state	HADS scores	Category	n (%)	Chi^2	P-value
Anxiety (n = 27)	8–10	Borderline results	13 (48.1)	0.037	0.847
	11–21	Anxiety disorders	14 (51.9)		
Depression (n = 17)	8–10	Borderline results	12 (70.6)	0.154	0.695
	11–21	Depressive disorders	5 (29.4)		
Aggression (n = 46)	3–4	Borderline results	32 (69.6)	7.043	0.008*
	5–6	Aggression disorders	14 (30.4)		

*statistically significant; n = number of people

Table 3. Testing the significance of differences in the emotional state levels in female (n = 30) and male (n = 40) patients suffering from cystic fibrosis.

Variable	Sex	X ± SD	t-test	P-value
Anxiety	F	7.8 ± 4.2	2.443	0.017*
	M	5.3 ± 4.2		
Depression	F	4.7 ± 3.5	0.719	0.474
	M	4.1 ± 3.9		
Aggression	F	3.9 ± 1.5	2.988	0.004*
	M	2.9 ± 1.4		

*statistically significant; F = female; M = male

Table 4. Testing the significance of differences in the emotional state levels in patients suffering from cystic fibrosis according to their age.

Variable	Age	X ± SD	F	P-value
Anxiety	from 14 to 16	6.2 ± 5.1	0.611	0.546
	from 17 to 20	7.2 ± 4.2		
	from 21 to 25	5.8 ± 4.1		
Depression	from 14 to 16	3.4 ± 3.9	1.618	0.205
	from 17 to 20	5.4 ± 3.6		
	from 21 to 25	4.1 ± 3.7		
Aggression	from 14 to 16	3.5 ± 1.5	0.427	0.654
	from 17 to 20	3.1 ± 1.4		
	from 21 to 25	3.4 ± 1.7		

Statistical analysis did not prove a significant relation between depression and patients' sex as opposed to anxiety and aggression. Both the level of anxiety and the level of depression were significantly higher in women than in men (Table 3).

Moreover, statistical tests did not confirm a statistically significant relation between anxiety, depression, aggression and patients' age (Table 4).

Evaluation of the quality of sleep by means of AIS

Evaluation of the quality of sleep showed that 37 (52.8%) cystic fibrosis patients reported sleep disorders: 15 (21.4%) patients complained of insomnia and borderline condition was diagnosed in 22 (31.4%) patients. A statistically significant difference in the patients' quality of sleep was observed ($Chi^2 = 7.06$; $p = 0.029$).

Evaluation of the relation between particular emotional states and the quality of sleep taking into consideration patients' sex

Statistical analysis proved that in the group of people reporting anxiety 23 (85.2%) patients suffered from sleep disorders (borderline:12; 52.2%, insomnia: 11; 47.8%) as well, whereas in the group of depressive patients sleep disorders (borderline: 6; 42.9%, insomnia: 8; 57.1%) appeared in 14 (82.4%) patients. In the case of respondents with irritability (aggression) symptoms sleep disorders (borderline: 16; 55.2%, insomnia: 13; 44.8%) occurred in 29 (63%) patients.

In order to verify the relation between anxiety, depression, aggression and the quality of sleep r-Pearson correlation coefficient was calculated. Statistical analysis proved that anxiety, depression and aggression in cystic fibrosis patients have a significant influence on their quality of sleep (Table 5).

Table 5. Testing the relation between emotional states and the quality of sleep in patients suffering from cystic fibrosis.

Variable	r-Pearson	t	p-value
Quality of sleep	0.631	6.712	0.000*
Anxiety			
Quality of sleep	0.621	6.534	0.000*
Depression			
Quality of sleep	0.293	2.528	0.014*
Aggression			

*statistically significant

Anxiety disorders accompanied by sleep disorders were diagnosed in 52.2% of women and 47.8% of men, depressive disorders with accompanying sleep disorders were reported in 42.9% of women and 57.1% of men whereas aggression (irritability) accompanied by sleep disorders appeared in 48.3% of women and 51.7% of men. The mean values of AIS were not significantly different between men and women (8.3 ± 5.1 vs 6.5 ± 5.1; t = 1.458; p = 0.149).

Evaluation of relation between patients' expiratory volume and their quality of sleep

In the group of patients diagnosed with bronchopulmonary in its early stage 19 (27.1%) patients reported sleep disorders. In the group with the moderate stage of the disease sleep disorders were reported by 11 (15.7%) patients, whereas in the group with severe stage of the disease 7 (10%) patients complained of problems with sleep. Statistical analysis which followed did not prove a significant influence of expiratory volume on the quality of sleep (r = 0.187; t = 1.566; p = 0.122).

Discussion

With a growing number of adolescents and adults suffering from cystic fibrosis there arises the need to pay more attention to patients' emotions and psychological sphere [23–26] and findings obtained from studies into this field may prove to be vital in minimalising the negative impact of the disease and maximizing the efficiency of medical treatment.

The key to achieve the main objective of the research was an attempt to evaluate patients' disorders in emotional sphere taking into consideration variables such as anxiety, depression, aggression (irritability) and the quality of sleep. The findings obtained in the individual study indicate a higher number of cystic fibrosis patients who were not diagnosed with anxiety and depressive disorders. Aggression (irritability) was identified in half of the patients. The level of anxiety and depression turned out to be the same in the 17–20 age group and the 21–25 age group. The highest level of aggression was identified in the 21–25 age group. The same level of anxiety and depression in the 17–20 age group and the 21–25 age group may mean both higher emotional awareness and the awareness of the consequences of the disease but also they may mean psycho-emotional maturity or accepting the circumstances determined by a particular health condition. Just as in the individual research, Harning *et al.* [12] also carried out an analysis of the incidence of anxiety and depression pointing out that the incidence of the emotions in question was not remarkably widespread among the patients. Similar results were obtained by Oliveiry's team [13], which also did not diagnose anxiety and depression in the majority of cases but discovered a close

relationship between negative emotional states and deteriorated quality of patients' lives. It is worth pointing out that the study was carried out in a group of adult patients. Another example of the research with results comparable to the results of the individual research was the one carried out by Quittner *et al.* [27], the authors of one of the biggest screening among teenagers suffering from cystic fibrosis, who proved the relationship between the incidence of anxiety or depression and patient's sex. In the research carried out by the Macedonian Academy of Science and Arts [28] cystic fibrosis patients were diagnosed with a moderate level of anxiety but a high level of depression and aggression, however, the evaluation of emotional state comprised only a narrow age group of patients (13–15) and involved the application of the scale adapted for this age group, which might have been the reason of different results. The age group examined is the age of adolescence and therefore the period of teenage rebellion, which may account for a high level of aggression among respondents.

The study carried out by Goldbeck *et al.* [29] took into account a wide range of patients' age. Similarly to the individual research, the authors' evaluation of patients' emotional state by means of HADS proved that in the majority of cases the level of anxiety and depression was normal. Anxiety was the most common in the 12–20 age group and depression, in turn, prevailed among patients aged between 21 and 30. It is worth pointing out that Goldbeck *et al.* applied different age groups in comparison to the individual research. The incidence of anxiety among patients aged between 12 and 20 may be accounted for by an increasing range of responsibilities which young people must take on, whereas a high level of depression in the 21–30 age group might be caused by the difficulties related to reaching adulthood. The results of the findings quoted above can be considered reliable because they refer to a diverse group of patients. Although the research did not confirm the incidence of depression in a significant number of patients, more attention should be paid to the risk which is posed by the incidence of anxiety. A potential threat that patients experiencing anxiety will in the future develop depressive disorders or even depression itself cannot be ruled out. Anxiety and depression may overwhelmingly dominate the quality of life of these patients, and thus, shorten their life.

Cystic fibrosis is a disease which prematurely shortens patients' life expectancy, it develops involving various stages of exacerbation and may impede patient's functioning in the society, which provokes negative emotions in young patients. Adolescence and reaching maturity is the time of numerous changes in the life of young people. The disease makes both women and men face extremely difficult circumstances, which provokes extreme emotions. The differences between the sexes are not only physical ones but, above all, they involve psychological divergence. Patients' sex determines their reactions and the way they deal with the disease, which was proved by the findings of the study mentioned above. When patients' sex is taken into consideration, the level of anxiety and aggression was higher in women than in

men. Statistical analysis did not prove a statistically significant difference between the incidence of depression and patients' sex. In the study carried out by Backström-Eriksson *et al.* [30] in the group of cystic fibrosis patients in Sweden and the United Kingdom, the authors noticed that there was a difference in the frequency of anxiety and depression incidence in women and men, pointing out that the level of anxiety was higher in women than in men. However, even though Backström-Eriksson *et al.* applied HADS, they excluded the part which evaluated aggression (irritability), which made it impossible to compare their results in this area with the results of the individual study. The fact that the comparably high level of anxiety was detected in countries with different cultural background (in Poland as well as in Sweden and the United Kingdom) indicates a strong relation between cystic fibrosis patients' sex and this emotional state.

Moreover, the evaluation of negative emotional states in patients outside the cystic fibrosis group seems to confirm the relation between anxiety and depression and patients' sex [31]. Further research in this field may be an important source for future analyses both for psychologists and health care professionals.

The attempt to recognize and understand the causes of the problem and carrying out further research into this field may have a significant impact on the proper diagnosis of negative emotional states in the patients and help to improve their health condition. Screening test, which detect negative emotional states, for example, application of HADS, seem to be both advisable and necessary because of their direct influence on the quality of life and life expectancy. Negative emotional states may be a significant factor responsible for the progress of the disease [32] and life expectancy [33]. HADS seems to be a useful screening tool because it can be applied not only by psychologists but also by doctors and nursing teams.

The quality of sleep is another essential factor in the case of cystic fibrosis patients. Appropriate sleep hygiene is important for young organisms. Sleep allows for proper regeneration, determines healthy growth, influences the progress of the disease and patient's psychophysical functioning understood in a broad sense. Bad quality of sleep is connected with an increased risk of the incidence of anxiety and depression [34]. The individual research proved that almost a half of the respondents had problems with sleep. This group consisted of both borderline patients and those reporting insomnia symptoms. The research did not prove the relation between the quality of sleep and expiratory volume. However, it must be pointed out that patients with acute respiratory failure, poor general condition and those treated permanently with oxygen therapy or undergoing mechanical ventilation did not participate in the research. Scientific findings and the results of the individual study of cystic fibrosis patients' sleep show a relation between the quality of sleep and various spheres of patients' life and their functioning [16, 35–40]. The results obtained unambiguously point out a high percentage of patients who suffer from sleep disorders of various

origins (e.g. obstructive sleep apnoea, delayed sleep, frequent waking up, respiratory disorders). Although the individual research did not prove a significant influence of lung functioning on the quality of sleep, it cannot be ruled out that this relation will not be discovered if another group of patients is examined or if the research is more extensive. Also the influence of factors different from the analysed ones cannot be excluded. The research described above might have been limited as well by a low number of participants. Continuation of research into human psycho-emotional sphere, quality of life and relations between various factors determining psychophysical and social functioning of cystic fibrosis patients might, in the future, be a vital issue which would improve standards of medical care and determine the patients' life expectancy.

Conclusions

Women experienced a higher level of anxiety and a higher level of aggression than men. No statistically significant relation was found between depression and patients' sex.

Most cystic fibrosis patients, regardless of their sex, complained of sleep disorders. Emotional state disorders have a significant influence on the quality of sleep. Along with an increase in the level of anxiety, depression and aggression, there increases a likelihood of sleep disorders.

No statistically significant relation was found between the quality of sleep and the stage of a bronchopulmonary disease progress in the examined group of patients.

Conflict of interest

None declared.

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