

Received: 2012.02.13
Accepted: 2012.09.04
Published: 2012.10.18

Patient's perception of the meaning of life in cystic fibrosis – its evaluation with respect to the stage of the disease and treatment

Ocena poczucia sensu życia pacjentów z mukowiscydozą z uwzględnieniem stopnia zaawansowania choroby i metod leczenia

Authors' Contribution:

- A** Study Design
- B** Data Collection
- C** Statistical Analysis
- D** Data Interpretation
- E** Manuscript Preparation
- F** Literature Search
- G** Funds Collection

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Summary

Introduction:

Cystic fibrosis (CF) is related to physical and mental barriers. The objective of this work was to evaluate and compare patients' perception of sense of life in cystic fibrosis in different stages of their disease and therapeutic methods.

Material/Methods:

The study group included 45 patients divided into 3 subgroups: after lung transplantation, waiting for lung transplantation and with cystic fibrosis in stable condition. The evaluation and comparison of patient's perception of sense of life and purpose of life was performed with the Purpose in Life Test.

Results:

All patients with CF felt their lives were meaningful and purposeful. However, their pursuits for designated aims depended on the progression of their disease.

Conclusions:

CF with its poor prognosis has a significant impact on patient's hierarchy of respected values and life priorities. High level of acceptance for suicidal behaviours observed in all diagnostic subgroups of patients with CF indicates a need for organized intensified psychological care.

Key words:

cystic fibrosis • the purpose and meaning of life

Streszczenie

Wstęp:

Mukowiscydoza jest związana z ograniczeniami natury obiektywnej, jak i trudnościami odczuwanymi indywidualnie. Celem badań była ocena i porównanie poczucia sensu życia u pacjentów z mukowiscydozą, z uwzględnieniem stopnia zaawansowania choroby i metod leczenia.

Material/Metody:

W badaniu uczestniczyło 45 chorych z mukowiscydozą w różnym stadium zaawansowania choroby: po transplantacji płuc, oczekujących na przeszczep płuc i w stabilnym stanie zdrowia. Oceniano i porównywano poczucie celu i sensu życia za pomocą testu Purpose in Life Test (PIL).

Wyniki:

Wszyscy z mukowiscydozą mają poczucie celu i sensu życia. Dążenia do osiągnięcia wyznaczonych celów uzależniają jednak od stopnia zaawansowania choroby.



Wnioski: Mukowiscydoza z jej niepomysłnym rokowaniem ma istotny wpływ na hierarchię uznawanych wartości i życiowe priorytety. Wysoki poziom akceptacji, wśród wszystkich podgrup diagnostycznych pacjentów z mukowiscydozą dla zachowań suicydalnych, generuje potrzebę organizowania wzmożonej opieki psychologicznej.

Słowa kluczowe: mukowiscydoza • poczucie celu i sensu życia

Full-text PDF: <http://www.phmd.pl/fulltxt.php?ICID=1014657>

Word count: 4169

Tables: –

Figures: 4

References: 8

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INTRODUCTION

Achieving happiness was, is, and surely will be the most important aim of human existence for every person. The success of this pursuit of happiness largely depends on individual resources of a person, i.e. one's resilience and the ability of coping in difficult situations, a system of ethical and moral values, and the type of meaning and purpose given to life by this particular person. The ability to find meaning in different situations and continuous relations with the world makes people valuable and able to make an effort reaching beyond current problems and tasks. When a person feels that his/her life makes sense and achieves the goals defined by himself/herself, this person describes his/her life as satisfying, which is inextricably linked to the sense of happiness. Patients suffering from cystic fibrosis (CF) undergo a difficult test of finding one's meaning and purpose of life. CF may cause anxiety and helplessness or depression. However, patients experience additional negative emotions, including fear of further fate and early death, since cystic fibrosis is an incurable and progressive disease.

The facts that no significant progress in medicine is expected in the near future and it is not possible to alter the structure of a gene leave patients without hope for recovery. The only alternative treatment, which is lung transplantation, does not change the prognosis in CF; it only prolongs life and influences quality of life, and is not available for every patient. The diagnosis of chronic disease brings multiple changes and challenges into the patient's life, leading to the disruption of normal physical, mental, and social reactions described as a crisis. Therefore, a question arises: how do patients find and give meaning to their lives when facing an incurable disease such as CF? Is a mature attitude of patients, stigmatised with this incurable illness, good enough to set personal objectives in their short life?

Numerous researchers have studied these issues, not only globally but also in Poland.

The objective of this work was to evaluate and compare patients' perception of the meaning of life in cystic fibrosis in different stages of the disease and treatment.

MATERIAL AND METHODS

The study took place between 2009 and 2010 in the Clinic of Pulmonology and Cystic Fibrosis, Institute of Tuberculosis and Lung Diseases in Rabka-Zdroj, and included patients hospitalised because of exacerbations of broncho-pulmonary disease or presenting for their follow-up appointments. The study group comprised cystic fibrosis patients in different stages of this disease, both men and women aged over 18 years. Fifty individuals were enrolled. The final number of analysed questionnaires was 45 since two patients died after lung transplantation and 3 respondents answered questions selectively. Three subgroups were created. Group I consisted of 10 patients after lung transplantation, performed in the Department of Cardiothoracic Surgery of the Vienna Medical University. Group II included 15 respondents in severe clinical condition and receiving oxygen therapy because of advanced bronchopulmonary changes. These patients were waiting for lung transplantation. Patients whose general condition was stable comprised the remaining 3rd subgroup. The following criteria had to be met in order to be in group III: no significant impairment of physical functioning and no need for oxygen therapy. All respondents gave their consent to participate in the study, which was anonymous. The consent of the Institute Director was obtained prior to the beginning of the study.

Research was based on the Purpose in Life Test (PIL), part B and C. A method of open sentences, as a projection technique, allowed wider description of patients' needs, assessments, and emotions in the context of the psychological concept. The research technique of open questions belongs to the group of projection procedures; therefore it has all the pluses and minuses of these techniques. In this type of study it is difficult to impose a certain type of answers, as happens in questionnaire-based studies. The analysis of answers started with grouping the endings of phrases (answers) into categories created on the basis of similar psychological contents.

No predefined categories were used. All of them were formed in an empirical way instead of a theoretical one. Categories were based on the content of sentence endings and the frequency of these endings. The next step was to

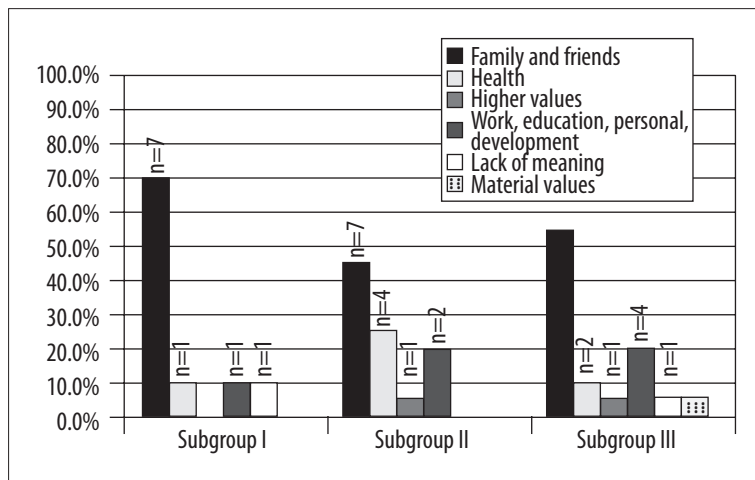


Fig. 1. The most important values in life

create items from the categories (unfinished phrases) into parent categories, relatively consistent as far as their psychological content was concerned. The following categories were defined:

1. General assessment of life and attitude toward one's own life (phrases: 1, 12, 15, 17, 24).
2. Attitude toward the future (phrases: 2, 3, 5, 7, 25, 26).
3. Evaluation and attitude toward the past (phrases: 4).
4. Attitude toward suicide – suicidal thoughts (phrase: 13).
5. Attitude toward disease, death, and suffering (phrases: 9 and 11).
6. Negative emotions: hopelessness, helplessness, sorrow, anxiety (phrases: 6, 8, 18 and 23).
7. Obstacles and coping strategies (phrases: 10, 14, 20).
8. Positive aspects of life: passions, satisfaction, energy (phrases: 16, 21, 22).

Part C of the test, regarding aspirations, ambitions, and life purposes, underwent only empirical analysis of free opinions.

In order to verify hypotheses about the relationship between the variables, χ^2 independence test was used. The hypothesis of independence was verified at a significance level of $p=0.05$. For the statistical analysis Statistica v.7.1 from StatSoft and Microsoft Excel 2000 from Microsoft were used.

RESULTS

The Purpose in Life Test (part B) results analysis vs. defined categories.

Category group: Assessment and attitude towards one's own life.

As far as the assessment of one's own life was concerned, positive emotional evaluation was the most frequent one (50% in subgroup I, 40% in subgroup II, and 26.7% in subgroup III). Negative emotional evaluation was reported by a similar number of respondents in all study subgroups, i.e. 26.7%. Emotional assessment reflecting uncertainty dominated in subgroup II (26.7%).

Life induced very positive emotions in 60% of patients after transplantation and 46.7% of respondents waiting for this

type of treatment, who assessed it in positive categories. The subgroup of patients in stable condition (subgroup III) evaluated their lives in the following categories: emotions reflecting uncertainty (35% of patients), cognitive aspects (25%), and even negative emotions (10%). Also, the subgroup of respondents waiting for transplantation expressed some negative emotions (20%). The only subgroup in which no negative emotions were reported comprised patients after transplantation.

The vast majority of respondents, from all studied subgroups (I, II, and III) and in the category of negative emotions as well as the negative-cognitive one, reported that the disease and other obstacles obscure positive aspects of their life. Only 10% of all patients after transplantation participating in this study presented attitudes towards life and the disease of positive nature.

Respondents from subgroup I, II, and III reported that their family and friends represented the greatest value for them (Fig. 1).

There were no statistically significant differences ($p=0.61$) between groups of people in principal meaning of life.

χ^2 ($n=40$, $df=4$)=2.68, $p=0.61$ (n.s.). Note: only considered statements: family and friends, health, work, education, self-development.

Maintaining health status was the principal meaning of life for 26.7% of patients waiting for lung transplantation (group II) and 10% of respondents from subgroup I and III.

Twenty percent of patient from subgroups II and III and 10% of respondents after transplantation (subgroup I) found the true meaning in their personal development (education, hobby, work). Ten percent of patients who underwent lung transplantation and 5% of respondents in stable condition admitted they found no meaning in their life.

Category group: Attitude towards the future and past.

The majority of patients from all subgroups believed they would be able to take care of their personal development and overcome obstacles. These respondents comprised 90%, 53.3%, and 60% of subgroup I (after transplantation),



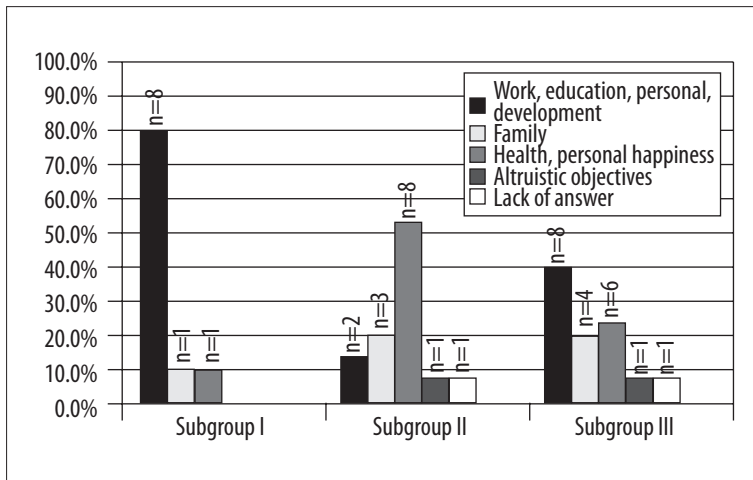


Fig. 2. The most important purpose of life

II (waiting for transplantation), and III (stable condition), respectively.

Fifteen percent of patients in good general condition reported detailed expectations from themselves and hoped they would be achieved.

The majority of our study population, i.e. 93.3% of patients waiting for lung transplantation (subgroup II), 80% of respondents from subgroups I and III, declared the desire for health and personal happiness. When asked about their greatest life ambitions, 80% of individuals after transplantation and 40% of patients in stable condition pointed to personal development, getting an education, and finding a job. However, only 13% of respondents waiting for lung transplantation cared about education and job.

Health and happiness were the most important aims of life for 80% of subgroup II (waiting for lung transplantation), 70% and 40% of subgroup I (after transplantation) and III (stable condition), respectively.

Having or starting a family was as important as personal development for respondents from subgroup III. However, in the two remaining subgroups this objective was indicated less frequently. Patients unable to precisely describe their goals and pursuits comprised 10%, 6.7%, and 25% of subgroup I (after transplantation), II (waiting for a transplant), and III (stable condition) (Fig. 2).

Subgroup I indicated statistically significantly more frequently ($p=0.033$) (compared to subgroup II and III) that the most important goals of their life are work, study, and personal development, while patients of subgroup II rarely emphasized these goals (compared to subgroup I and III); χ^2 ($n=40$, $df=4$)=10.49, $p=0.033$. Note: Due to the number of respondents' answers, work, education, development of self, family, health, and self-happiness were taken into account.

Respondents also completed phrase number 25, "When I think about the world, I believe...", and the same number of patients (60%) from group I and III presented a critical opinion about the world. A similar ending of this sentence was given by 40% of respondents waiting for lung transplantation. An ambivalent attitude was manifested by

20, 40, and 35% of individuals comprising subgroup I, II, and III, respectively.

A positive perspective of the world was reported by 20% of patients from subgroup I and II, whereas in the remaining subgroup of patients in stable condition this ratio was only 5%. When asked about their attitudes towards the past, the majority of respondents from subgroups I and III felt they had some achievements. However, fewer patients waiting for transplantation (subgroup II) were convinced about their successes.

Category group: Attitude towards suicide and suicidal thoughts, and attitude towards disease, death, and suffering.

The biggest number of people accepting suicide as a form of problem solution was recorded among patients waiting for a transplant (46.7%). Fewer respondents from the remaining two subgroups (after transplantation and in stable condition) approved of suicide (Fig. 3).

There were no statistically significant differences ($p=0.45$ n.s.) between groups of people to attitudes toward suicide; χ^2 ($n=45$, $df=4$)=3.71, $p=0.45$ (n.s.)

A negative attitude toward death was presented by 40% of respondents after lung transplantation, 46.7% of those waiting for a transplant, and 20% of patients in stable condition.

For respondents from all three subgroups (I, II, and III) accepting this phenomenon, death was "the beginning of another existence" or "meeting their God" (Fig. 4).

There were no statistically significant differences ($p=0.08$ n.s.) between the two groups of people to attitudes toward death. Although more people of subgroup III (compared to other groups) treat death as an inevitable phenomenon, the difference is not statistically significant. Despite the fact that fewer people in subgroup I (compared to other groups) treat death as an inevitable phenomenon, the difference is not statistically significant; χ^2 ($n=41$, $df=4$)=8.42, $p=.077$ (n.s.). Note: Answers taken into account were only: acceptance of death; a negative attitude to death; treating death as an inevitable phenomenon.

40% of patients in stable clinical condition and 13.3% of those waiting for a transplant perceived death as a natural

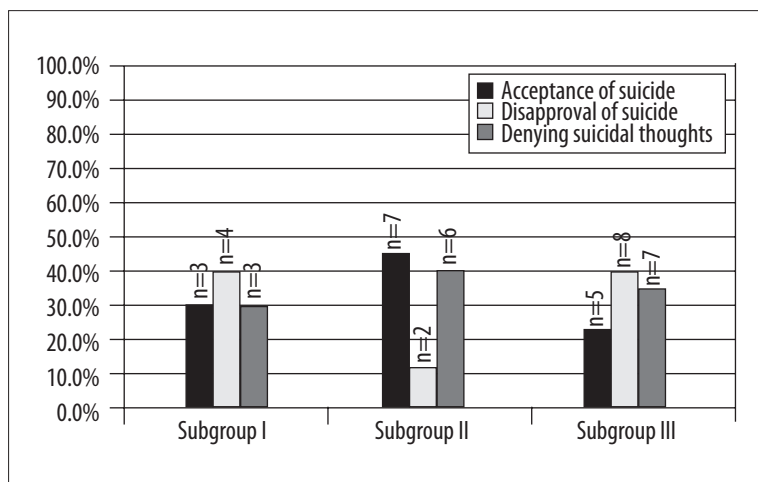


Fig. 3. The attitude towards suicide

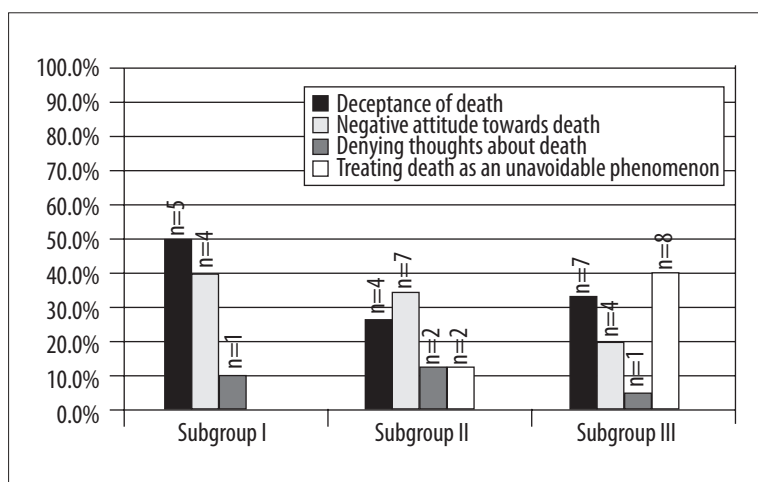


Fig. 4. The attitude towards death

and unavoidable phenomenon. Not many respondents from all subgroups thought about death. Disease and suffering were a re-evaluating factor and “a gift that helps understand life” for 60% of respondents in the three subgroups. These patients noticed positive aspects of suffering. However, according to 40% of individuals comprising subgroups I, II, and III, disease and suffering were a source of incomprehension and induced negative emotions in them.

Category group: Sense of helplessness, hopelessness, and fear.

The causes of feeling hopeless in all subgroups included: personal weakness (50% and 40% from subgroup I and III, respectively), disease (30% in subgroup I, 33% in subgroup II, and 20% in subgroup III), and external factors, which cannot be altered (close to 20% of respondents in every subgroup). A significant number of respondents from subgroup I and II (60%) and more than half of patients comprising subgroup II (53%) manifested a strong sense of helplessness and hopelessness. Then again, the number of individuals reporting fear for their health was close to 50% in subgroups I and II, and 35% in the remaining subgroup of patients in stable clinical condition (III).

Category group: Obstacles and coping with them.

Almost every respondent disapproved of behaviours where alcohol and drugs are used to solve one’s problems. Only

15% of patients in stable clinical condition and 6.7% of those waiting for lung transplantation accepted this form of problem solution and overcoming life difficulties. However, the majority of respondents comprising our study population described how other people’s help was essential and priceless to them. An ambivalent attitude towards that kind of support was manifested only by 20% of respondents from subgroups I and III. The disease was the major factor stopping patients from achieving their goals according to 86.6% of individuals with CF waiting for lung transplantation. When asked about the factors preventing them from reaching their objectives, patients comprising subgroup I and III indicated a lack of courage, fear of the unknown, and external circumstances.

Category group: Positive aspects of life: passion, satisfaction, energy.

For all our respondents the positive aspects of life were related to practising hobbies, personal development, and having relations with other people. A different opinion was presented by 13% of CF patients waiting for lung transplantation (subgroup II), who saw no positive aspects of life.

When asked about the source of satisfaction, 90% of patient after transplantation (subgroup I) said it was beating the disease, whereas according to 10% it was living a good life. Respondents comprising subgroup II and III (20%)



reported that their families and friends also were very important. These subgroups were characterised by a higher proportion of people who believed they lived a good life (26.5% in group II, and 50% in group III). Still, there were also individuals who had no sense of satisfaction.

As many as 80% of CF patients waiting for a transplant focused their entire energy on their fight against the disease. However, this problem of disease did not exist for respondents after lung transplantation (70%), who directed their energy toward family and social life as well as their personal development (20%). Subgroup III consisted of individuals focusing their energy on family (40%) and with no directly defined goals (30%).

The assessment of life purpose and meaning – free statements from part C of the test.

The analysis of free statements of respondents after lung transplantation showed that their pursuits, goals, and ambitions mainly focused on happy family, investments in personal development, and becoming independent. Letting go of fear and uncertainty became a dream for the majority of study participants starting with the moment when their lives ceased to be controlled only by their fight for survival.

All efforts and pursuits of CF patients waiting for a lung transplant are focused on one objective, i.e. to maintain the best possible clinical condition until lung transplantation. Their dreams beyond the scope of transplantation concern the ability to start a family, better education, and personal fulfilment in their professional life.

Respondents in stable clinical condition most of all dream of maintaining their current health status as long as possible. The majority of these patients saw the achievement of their dreams and pursuits in their personal development, finding a job, achievement of stability in their emotional life and leaving something behind for other people.

DISCUSSION

The sense and awareness of the purpose and meaning of life is an important factor improving psychic integration of people. CF and its progression is the cause of numerous limitations of both life and functioning domains. They make it difficult to meet the need for safety and independence. As far as the functioning domain is concerned, CF interferes with the fulfilment of personal goals set by the patient. This disease makes patients fear for their future, causes tension and stress, and may lead to a loss of faith in the meaning of life and result in a mental crisis. Quitner et al. [8] showed in their research that patients with CF manifested higher ratings of depression when compared with the healthy population. However, these findings were not confirmed in studies performed among adolescents with cancer or CF by Cepuch and Dębska, which showed that anxiety and depression were recorded among few respondents in both studied groups [3].

Our research included respondents with CF divided into three diagnostic subgroups: after lung transplantation, waiting for transplantation, and in stable clinical condition. Our results showed that patients assessed their lives

positively in both emotional and cognitive aspects, regardless of the subgroup type they belonged to.

Cepuch and Wordliczek studied adolescent patients with cancer and rheumatic disease and presented similar results, i.e. respondents were satisfied with their lives despite their serious disease [4]. For these patients, just like for those with CF, life was meaningful. In contrast, studies concerning healthy adolescents showed poorer sense of the meaning of life, existential frustration, and a sense of emptiness [5]. Healthy young people especially appreciate the values concerning psychosocial functioning, i.e. moral, hedonistic, and spiritual. At the same time, they believed that health-related values were unimportant [7].

Therefore, chronic disease does not determine the lack of meaning and satisfaction of life. A personal concept of the world and one's beliefs, in which values play a special role, are built on this basis. The sense of the meaning of life is in close relation with these beliefs and values. Our study showed that health and family values were highly appreciated by respondents from all three diagnostic subgroups. Personal development was significantly less important whereas material values were the least significant.

When asked about their attitudes towards the future, plans for life, desires and aspirations, the majority of respondents hoped to be able to overcome all obstacles and take care of their development. The desire for personal happiness is closely related to health because only then may a person achieve multidimensional development. Young patients after lung transplantation and those in stable clinical condition presented realistic assessment of their abilities. All actions taken with effort by patients waiting for a lung transplant were determined by a single goal, i.e. lung transplantation. For respondents waiting for lung transplantation this medical procedure was the source of an optimistic view of the future and the only way of recovery. A similar situation concerned patients requiring dialysis and young diabetics [6].

We also analysed the level of patients' satisfaction in the context of their past. It may be concluded that respondents from all three diagnostic groups found the source of greatest satisfaction in the achievement of previously defined goals. Unfortunately, quite a high percentage of patients waiting for lung transplantation and those in stable clinical condition had no sense of any achievements. It is likely that the subjective sense of a lack of personal achievements resulted from poorer self-esteem, which may be observed among patients with poor prognosis. Furthermore, the progression of disease may preclude respondents from achieving their goals, which is then reflected in respondents' lack of sense of personal achievements in the past.

The attitude towards suicide is a proof of the sense of purpose and meaning of one's life. However, it seems disturbing that despite significant disapproval of this solution of problems still a similar percentage of respondents accept suicidal behaviours, especially among patients waiting for lung transplantation. High support for these behaviours is surprising since the same group of patients believed that life was the greatest value. The diagnosis of a disease posing a threat to one's life often triggers a mental

crisis – an existential one. Thoughts and plans of suicide may occur every time this type of crisis happens. It is defined as a “suicidal crisis”. Suicidal behaviours comprise a chain of events starting with one’s imagination of suicide as a welcomed value.

The fact of a positive attitude towards suicide among even the smallest group of respondents should be a subject of concern and encourage preventive actions. First of all, the intervention should provide help for a patient so he/she could better understand his/her own feelings, discharge negative emotions, and define a personal system of values. Taking into consideration the high score regarding the approval of suicide in all studied subgroups of patients with CF, any possible action explaining this phenomenon and preventing suicidal behaviours seems to be the most appropriate. The attitude towards death seems to correlate with respondents’ attitudes concerning suicide. The majority of patients after lung transplantation and those in stable clinical condition accepted death and believed it was a natural phenomenon. The lack of acceptance was characteristic for respondents waiting for a lung transplant. Most patients treated their disease as a factor defining their value, which enabled the patient to understand what type of a “gift” life was.

The sense of purpose and meaning of life determined the level of one’s hope or hopelessness. The level of one’s hope significantly influenced positive perception of oneself and one’s disease. Then again, hopelessness negatively correlated with self-esteem and showed a positive correlation with depression [4].

High level of self-esteem leads to the conviction that a person could cope with difficulties and overcome them easily. The analysis of our results indicated sources of negative emotions and hopelessness. According to the majority of respondents from all three subgroups the disease and limitations resulting from it as well as the ability to overcome one’s own weakness were the cause of helplessness. They were helpless when facing unpleasantness from the surrounding environment and other people. The ability of empathic feeling with patients suffering from cystic fibrosis and understanding their problems are a fundamental condition of help and support adequate to patients’ expectations. This support must be multidirectional, and should be balanced and subtle in order not to hurt patients’ feelings. Our results analysed in this paper indicate to what extent patients with cystic fibrosis need our help. None of the respondents waiting for lung transplantation could imagine their life without other people’s help. Also, help and support for patients after lung transplantation and those in stable clinical condition is priceless and necessary.

The fact that the vast majority of respondents did not approve of alcohol and drugs as a method of problem solution is very edifying and requires special attention. Clear

and strong opposition towards these behaviours confirms the belief that health and life have the greatest value for patients suffering from cystic fibrosis. The use of drugs in order to minimise problems and life difficulties also met with disapproval from most healthy adolescents [7]. However, a disturbingly high number of young people with hearing problems approved of stimulants [1].

Negative emotional conditions in patients with CF were balanced by their long-term goals and aspirations. These positive aspects, which were found by respondents in their life, despite all the odds, in all studied subgroups, made patients willing to find energy to try and desire to keep on living. None of the obstacles in life of patients with CF resulting from their disease can be denied. However, this is not a sufficient reason for respondents to perceive their life as unsatisfying. This conclusion was confirmed by the fact that the vast majority of patients after lung transplantation believed that their successful struggle against the disease was the greatest source of satisfaction. Similar studies among individuals with Crohn’s disease [2] and young diabetics [6] reported high rating of satisfaction with one’s life, both the present and predicted ones.

General analysis of results obtained from studies concerning patients with CF showed that these respondents found and knew what the meaning of their life was despite their severe disease with poor prognosis and regardless of the diagnostic subgroup they currently belonged to. Those who underwent successful lung transplantation felt stronger and had more faith in their abilities.

Research focusing on the sense of purpose and meaning of life among patients with cystic fibrosis comprises pioneering studies. Furthermore, due to the fact that there is a small number of patients after lung transplantation as well as those waiting for a lung transplant, these studies are ambiguous.

Detailed recognition of their problems would certainly promote creation of an adequate system of support.

CONCLUSIONS

1. Patients with cystic fibrosis had a sense of purpose and meaning of life. Their desire to achieve personal goals depended on the stage of their disease.
2. Despite all difficulties resulting from their illness, the majority of respondents from all subgroups believed their lives were satisfying.
3. Cystic fibrosis with its negative prognosis had a significant influence on the hierarchy of accepted values and life priorities.
4. High levels of approval of suicidal behaviours presented by patients with CF from all diagnostic subgroups suggests the need for increased psychological care.

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The authors have no potential conflicts of interest to declare.