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# Evaluation of anxiety and depression incidence in adolescents with cystic fibrosis or malignant diseases

## Abstract

**Background.** Malignant diseases and cystic fibrosis are responsible for long-lasting states of frustration and suffering, which particularly affect adolescents. Considering potentially dangerous effects of anxiety and depressive episodes, prompt and reliable diagnosis and therapy become especially important for both quality of life and its preservation. Problems with the evaluation of incidence of anxiety and widely understood depression, and contradictory results found in literature, encouraged researchers to attempt the assessment of incidence of chosen negative emotions in adolescents.

**Material and methods.** The study group comprised of adolescents and young adults, aged from 14 to 21, hospitalised because of malignant diseases ( $n = 78$ ; group I) and cystic fibrosis ( $n = 53$ ; group II). The incidence of anxiety and depression was evaluated with the Hospital Anxiety and Depression Scale (HADS).

**Results.** Anxiety was observed in 25% of CF patients and 14% of cancer patients whereas depression was diagnosed in 10% of group I patients and 6% of group II respondents. The study groups showed no difference in the level of anxiety and depression ( $p \geq 0.05$ ). No statistically significant correlations between patients' groups, divided in regard to the level of anxiety and depression, were found ( $\chi^2 = 2.4$ ,  $p = 0.3$  vs.  $\chi^2 = 1.04$ ,  $p = 0.59$ ). The multivariate analysis (ANOVA) also confirmed that anxiety and depression incidence did not depend on diagnosis ( $R$  Rao = 1.5,  $p = 0.23$ ). Both groups showed strong positive relation between the level of anxiety and depression ( $r = 0.66$ ,  $p = 0.001$ ).

**Conclusions.** The level of anxiety and depression was observed in a small proportion of respondents. Adolescents suffering from CF and malignant diseases showed no difference in regard to the anxiety and depression levels. However, it could be possible that patients hid disturbing symptoms (anxiety and depression). Therefore, special care must be delivered to those whose level of depression and anxiety are close to the upper norm limit.

**Key words:** adolescents, anxiety, depression, cystic fibrosis, malignant diseases

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## Introduction

Adolescence (i.e. according to the WHO, age from 14 to 21 years) is a period of significant physiological and psychological changes, characterised by a meaningful fluctuation of mood and emotions. There is a huge need for psychic comfort so a young person may become independent, find acceptance among peers, face the future and make serious decisions about education, career and life targets [1, 2].

The chronicity and unpredictability of malignant diseases and fatal course of cystic fibrosis (CF) may prevent young people from fulfilling social roles, but it also may encourage negative emotions. These negative emotions increase suffering and radically decrease patient's quality of life through making adolescents vulnerable to their disease [3]. Meanwhile, the incidence of negative emotions of depressive character or fear may determine young person's sense of life and purpose [4, 5]. The sense of life becomes especially meaningful for adolescents due to accomplishing the "milestones" specific for this age.

Anxiety is a signal of a threat in the psychic sphere and after finding a way to human consciousness it affects one's behavior. Young patients with chronic anxiety become more vulnerable to high level of emotional distress. Mental discomfort is magnified by many limitations experienced by adolescents with malignant diseases or CF e.g. limitations of physical activity, periods of extreme fatigue, pain and deprivation of many needs [1, 3, 6]. The power of anxiety influence on human's development significantly increases in adolescence. Young people may also experience problems concerning planning their future when disease relapses occur and prognosis is uncertain (malignant diseases) or, especially when the life-long prognosis is fatal (CF), and their disease is connected with re-hospitalization and separation from the closest [6–8].

Depression is mostly the consequence, threatening most adolescents with cancer or CF. The expression "depressive syndrome" or "depression" has various meanings. It is commonly used to describe short states of worsened mood or discouragement or even "decreased well-being". But it also may describe mental disease by itself, with extremely serious psychotic symptoms. The most frequent mistake is made when commonly understood "depression" is confused with organic depression, meaning disease syndrome where worsened mood is only one of many symptoms [9]. This way it may cause numerous confusions in diagnostic process, when varying organic depression from the depressive state symptoms of fatigue, frustration or decreased emotional status

due to many stressful circumstances [10]. In chronic and severely ill patients, even depressive behavior stays undiagnosed and untreated because of common believe that "depressive attitude" always accompany the fatal disease and is universal reaction to a serious disease. Very often neurovegetative symptoms like weigh lost, sleep disorders or emotional depressive disorders are perceived as cancer symptoms [11]. The more complicated situation is to be observed in patients with CF.

In consideration of potentially dangerous effects of anxiety and depressive episodes, prompt and reliable diagnosis and adequate therapy seem to be extremely important in both aspects: quality of life and its preservation. Prolong anxiety, but especially the course of depression, not only complicates adjustment to the disease and its therapy, but also affects endocrine and immunologic functions [12, 13].

Failure in overcoming physiological problems related to adolescence, often characterized by depressive behavior, as well as fatal disease-oriented chronic anxiety and depression, may disturb the process of establishing competences and leaving young person vulnerable to further depressive episodes, which were pointed out by Evans [14] and Tebbi [15]. The diversity of anxiety presentations and its prevalence must encourage the therapeutic team to find the source and discharge anxiety-forming situations.

## Purpose

The purpose of this work was to evaluate the incidence of negative emotions (depressive character and anxiety) in adolescents hospitalized due to CF or malignant disease. The following research thesis was formed in relation to the general purpose:

1. Is there any anxiety or depressive behavior observed in the studied groups?
2. Does the level of depressive behavior and anxiety differ between the studied groups and does it depend on diagnosis?
3. Is there a relationship between anxiety and depression within each group and in both groups together?

## Material and methods

The study included 131 young males and females, aged from 14 to 21. Among them, 78 suffered from cancer (group I) and 53 (group II) were CF patients (Table 1) The study included patients with CF and malignant diseases because of their common features i.e. disease chronicity, threat of premature death (in CF patients death is inevitable), painful and burdensome therapy and diagnostics, frequent

**Table 1. Demographic characteristics of the studied groups**

Groups	n	Aged				Sex	
		x	SD	Min	Max	Female	Male
Group I (cancer)	78	16.6	1.4	14	20	35 (42.7%)	47 (57.3%)
Group II (cystic fibrosis)	53	18.7	2.5	14	21	28 (52.8%)	25 (47.2%)

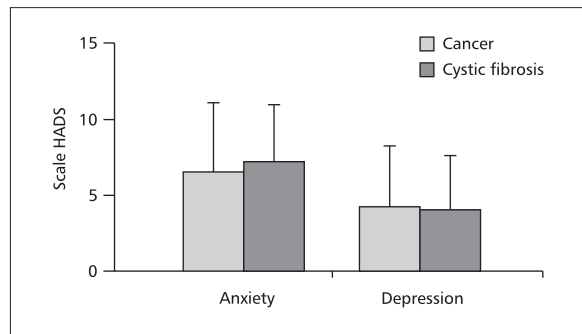
and long hospitalisations and worse social contacts (e.g. individual education).

In order to conduct the study among adolescents with oncological diseases, the consent of the Bioethical Committee, Jagiellonian University (KBET/395/B/2003) was obtained and the Scientific Research Committee by the Institute of Tuberculosis and Pulmonary Diseases in Warsaw (KE-29/2004) approved the study concerning CF patients.

Written consent signed by the participant and his/her legal guardian was the vital condition of inclusion in the study. The study involved patients with leukaemia, lymphomas, bone tumours and soft tissue sarcomas, as well as patients with cystic fibrosis, proofed by biochemical sweat test and DNA analysis.

Patients qualified for this study were in different stages of diseases. However, patients with very advanced and terminal illness were excluded because of ethical reasons. Adolescents with acute exacerbations of cystic fibrosis and patients with coexisting diseases and disorders of other organs and systems, which may cause more negative emotions, were excluded from the study.

Research methods included medical record analysis, survey questionnaire and the Hospital Anxiety and Depression Scale (HADS), which is a tool for the evaluation of anxiety level and depression intensity in the population of patients with somatic not psychiatric disorders. The HADS may be used as a screening tool not only by psychologists but also by other members of the therapeutic team. The HADS scale is believed to be a reliable and apt method for the assessment of negative emotions. Despite the fact that this scale was meant for adult patients, it may be successfully used in the group of adolescents without any decrease in its aptness and reliability [16–21]. In authors' research the evaluation of negative emotions incidence (i.e. anxiety and depression) was given with mean raw data. The data range was between 0 and 21. Results were interpreted with the scale of anxiety and depression using three categories: "no disorder" (0–7 points), "borderline status" (8–10 points) and "presence of disorder" (11–21 points).



**Figure 1.** Mean values of anxiety and depression level (mean values were given with mean error)

**Table 2. Assessment of fear occurrence in examined groups with Hospital Anxiety and Depression Scale**

Groups	Anxiety		
	Lack of disorders	Borderline	Disorders
Group I (n = 78)	45 (57%)	23 (29%)	11 (14%)
Group II (n=53)	25 (47%)	15 (28%)	13 (25%)
Significance of differences	NS		

Ch2 (n = 131, df = 2) = 2.40, p = 0.30; NS — no significant

Obtained results were analysed with the Mann-Whitney U test, Chi-Square Independence Test, [R] Pearson's correlation coefficient and multivariate analysis of variance Anova (Manova).

**Results**

The evaluation of negative emotions (anxiety, depression) incidence in the studied group was presented with the mean values of raw data i.e. the sum of points in a given scale, and then categorised.

The mean score for anxiety in group I was 6.68 ± 4.60 and in group II — 7.3 ± 4.04. For depression those scores equalled 4.35 ± 3.85 and 4.10 ± 3.65 in group I and II, respectively. Statistical analysis showed that the mean values of anxiety and depressive disorders intensity didn't significantly differ between those groups (p = 0.23 in group I and p = 0.73 in group II). (Fig. 1).

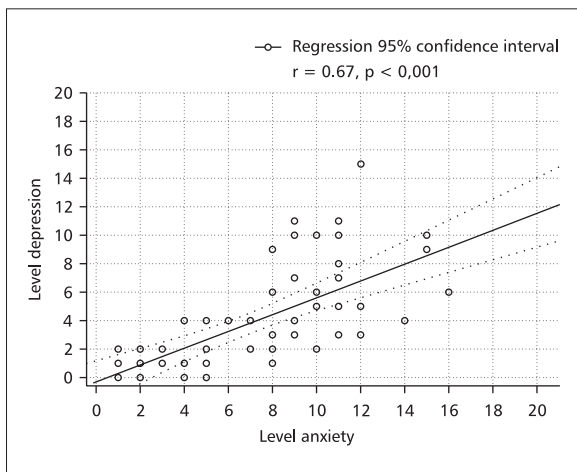
Evaluation results of anxiety and depressive disorders were grouped into three categories: no disorders, borderline, and presence of disorders. Table 2 and 3 show percentage distribution of those results. Anxiety disorders were observed in 14% of cancer patients and 25% of CF patients, while depressive symptoms were found in 10% and 25% of corresponding groups. Statistical analysis didn't

**Table 3. Assessment of depression occurrence in examined groups with Hospital Anxiety and Depression Scale**

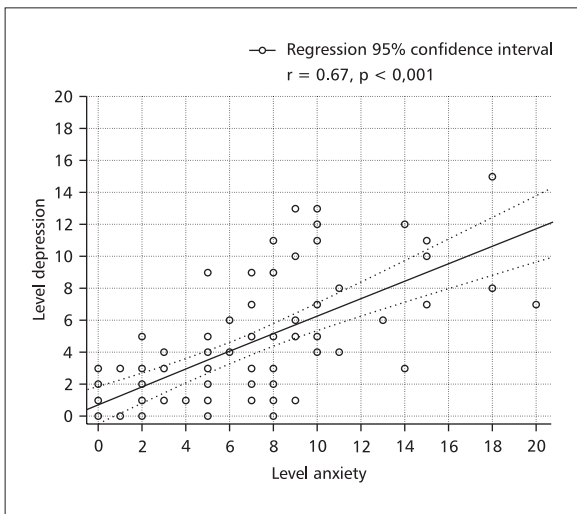
Groups	Depression		
	Lack of disorders	Borderline	Disorders
Group I (n = 78)	63 (80%)	8 (10%)	8 (10%)
Group II (n = 53)	43 (81%)	7 (13%)	3 (6%)
Significance of differences	NS		

Ch2 (n = 131, df = 2) = 1.40, p = 0.59; NS — no significant

reveal any significant correlation between separated evaluation categories of anxiety and depressive disorders and the diagnosis (cystic fibrosis, malignant diseases).



**Figure 2. Correlation between anxiety and depression for group II (group cystic fibrosis)**



**Figure 3. Correlation between anxiety and depression for group I (cancer)**

Strong positive correlation was proven between the level of anxiety and depression in each of the studied groups (Fig. 2, 3). Similar correlation was observed while analysing both groups together ( $r = 0.658, p < 0.001$ ).

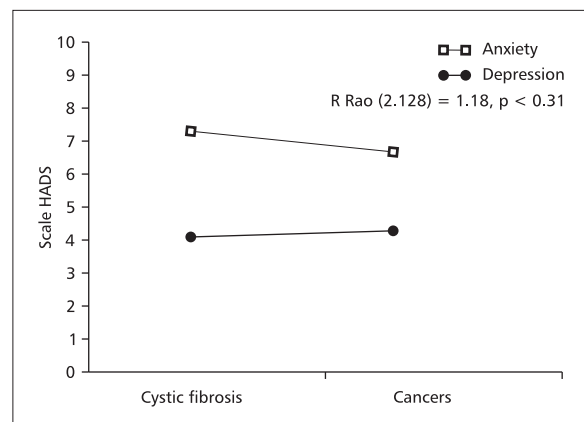
No statistically significant relation between the incidence of anxiety and/or depression and the type of disease (inclusion to a studied group) was found while assessing connections between the incidence of negative emotions and the fact of belonging to a given group of patients (Fig. 4).

Patients were qualified to age subgroups within the studied samples (CF and malignant disease) because the range of respondents' age was wide. It was assessed whether there is a relation between belonging to an age group and anxiety and depression occurrence. Statistical analysis showed no such connection (Table 4). However, it must be noticed that malignant disease group comprised only of 12 patients 18 years old and older (15.4%) while CF group consisted of 35 young adults at the age of 18 and more (66%), which might have affected our results. No analysis of negative emotions occurrence vs. gender was performed because of too small study group.

Presented result must be treated as a preliminary report due to the fact of generalisation and shall become a subject for future complex research.

## Discussion

Negative emotions accompanying the disease are something quite natural and included in the ways of managing the illness. Therefore, it is important not only to find out whether they occur but also how they are expressed, how strong they are and whether they affect patient's quality of life.



**Figure 4. Dependency between anxiety and depression level and belonging to the study group (range of scale was limited to 10)**

This study showed that both anxiety and depression were observed in a small group of adolescent patients with CF, and those with malignant diseases. These results are consistent with outcomes presented by Kellerman et al. [22], Zeltzer et al. [23], or Tebbi [15], Canning et al. [24] and Allen et al. [25]. All of the abovementioned authors showed that levels of anxiety and depression observed in adolescents with diagnosed malignant diseases weren't higher than those noted in the general population of teenagers. Similarly, Trask et al. [26] indicated that young patients experience minimal level of emotional suffering in different stages of the disease. As far as CF patients are concerned, most studies show that their emotional problems don't vary from those observed in healthy people, and are the same or even smaller than the problems of patients with other chronic diseases [1, 27].

However, it must be underlined that young patients in bad health condition or terminal disease were not included in any of abovementioned studies. The authors would like to emphasize that this group of adolescent patients may experience significantly stronger suffering. Therefore, in order to draw final conclusions further research in this group of patients must be done.

The study concerned cancer and CF adolescent patients but it didn't assess other variables, which may significantly affect final results e.g. family functioning, educational achievements etc.

In addition, no relation between the incidence of negative emotions in adolescents and the type of diagnosed disease was found. Von Essen et al. [28] presented similar results. His research also showed that depression wasn't directly related to the diagnosis itself but rather to discomfort accompanying a chronic disease e.g. pain. This is consistent with other publications stating that negative emotions predispose patients towards higher perception of pain, on one hand but on the other one, continuous pain in its effect may influence the incidence of negative emotions and fatigue [29, 30]. Finally, it leads to what Wade and Price [31] called suffering. Analysed publications ignored the problem of pain in CF patients assuming it to be an unspecific symptom. However, clinical practice suggests that pain in this group of patients may accompany osteoporosis, spinal curvature, arthritis, sinusitis, emphysema and complications in the alimentary tract [32].

The level of obtained information on patient's health status is one of the important factors affecting the incidence of negative emotions. Last [33] pointed to lower levels of anxiety and depression

observed only in adolescents who were fully informed about their disease. Also, CF patients handle well the information that their disease may shorten their lives. Therefore, next studies should answer the question whether obtaining full information about patient's disease decreases the level of anxiety and depression.

According to Hodson [34] some patients with cystic fibrosis may require psychiatric therapy in the final stage of their disease. De Jong et al. [35] and Britto et al. [36] proved that CF patients had lower outcomes in physical activity when compared with psychosocial functioning.

The review of publications showed that emotions of adolescents and young adults with CF can oscillate with different strength from the need of independence to being dependent on others in certain situations e.g. worsened clinical status, waiting for transplantation etc. [34, 37–39]. Research indicated that the feeling of having control over emotions leads to the improvement of health status, hence better quality of life. As a result, patients start to believe that they can control negative events.

Authors own studies and publications quoted here allow explaining low level of anxiety and depression presented by young patients. Most researchers (according to Kazak et al. 1995 in Pilecka [6]) believe that paradoxically low level of depression intensity in young patients results from effective control over negative emotions, which is due to well developed managing skills, good support or malleability of their own behaviours. Depressive states may be hidden and consciously denied. Also, self-report questionnaires and scales utilised in the studies describe subjective picture of emotional difficulties experienced by a sick teenager rather than picture drawn by the closest people, which are not necessarily the same.

It must be underlined that disease is accompanied not only by negative emotions but also positive ones e.g. satisfaction, hope, joy, the sense and will of life. These occur when the following needs are fulfilled: acceptance, care, support, and the disease is perceived as a challenge [40]. Research by Majkovicz [5] proved that the sense of life and its purpose increased the quality of patient's life and decreased the level of negative emotions (anxiety, depression, anger). Pilecka [6] emphasizes the fact that disease, understood as a challenge or a problem to be solved, results with finding the sense of life, which becomes a chance to develop mature and internally rich personality. It seems that the following skills: recognition and managing experiences related



to the disease, negative emotions especially, are necessary effort to overcome the illness [41, 42].

Prolonged course of disease, uncertainty of therapy, irregularity resulting from the disease itself and aggressiveness of cancer and CF therapy may affect the sense of life and its purpose of young patients, which are determined by the level of their hope or its lack. Self-esteem is a result of person's own value assessment and it becomes a critical aspect of adolescent's development. It may also affect young patient's beliefs concerning future achievements.

Malignant disease and cystic fibrosis bring many symptoms of physical and/or psychic distress, which was proven by research in that field [42, 43]. Early detection of anxiety and depression symptoms in patients with cancer or CF becomes priority, especially that more evidence proves an existing relation between depression and disease progression e.g. through endocrine and immunologic functions in cancer [11, 44].

In the light of authors' results and publications review, which present divergent outcomes, further studies are necessary in order to explain this phenomenon. However, it may be assumed that discrepant results are due to both different population characteristics in the studied groups and the choice of measurement tools or different measures. Most of all, the inconsistency of outcomes proves that relations between one person's qualities, environmental conditions and the course of young man's development are very complicated.

## Conclusions

1. Anxiety and depression were observed in small percentage of patients in both studied groups.
2. Adolescents with cancer or CF did not differ as far as the level of anxiety and depression was concerned. However, it can't be assured that patients were hiding disturbing symptoms (anxiety and depression). Therefore, special care must be delivered to those patients whose depressive and anxiety symptoms met the norm's borderline.
3. Adolescents and young adults with high level of anxiety are more likely to develop depressive disorders, which should be considered in early detection and making care plan for those patients.

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