

EMOTIONAL HEALTH IN CHILDREN AND ADOLESCENTS WITH CYSTIC FIBROSIS

Nada Pop-Jordanova¹, Aneta Demerdzieva²

¹ Macedonian Academy of Sciences and Arts, Skopje, R. Macedonia

² Acibadem Sistina Hospital, Skopje, R. Macedonia

Corresponding Author: Macedonian Academy of Sciences and Arts, Bul. Krste Misirkov, br. 2, 1000 Skopje, R. Macedonia, E-mail: popjordanova.nadica@gmail.com

Abstract

Although modern therapeutic procedures have considerably improved the survival and the quality of life of children with cystic fibrosis, the relevant psychological aspects have been still insufficiently considered similarly to the other chronic diseases.

The aim of this research was to evaluate the emotional health: psychological characteristics and adjustment of CF children and their family coping.

The study comprises 25 CF children, mean age 13.13 ± 2.29 years (23 boys and only 2 girls), selected from total 60 actually treated children for CF. Children were examined in the period of improved health conditions (without superinfection, wheezing or gastrointestinal problems). Obtained results are compared with a control group of 25 healthy children of the same age, selected by random from primary schools.

The psychometric instruments used were: Kohs Design Test, Child Behavior Checklist, Eysenck Personality Questionnaire, General Anxiety Scale, Emotional Profile Index, MMPI-201 and Human Values Test, together with two projective tests of drawing (Machover and Corman).

The unexpected good psychological results obtained from psychometric instruments could be explained by the fact that CF children accept the real situation and express vivacity. However, their deep feelings of fear impose on them high level of self-control and resistance. The results obtained for CBCL presented CF children as immature, with accentuated aggressiveness in interpersonal relations. The most important problem is related to the delay of puberty changes, leading to low self-esteem.

Generally, family members cope relatively well with the disease in children, in spite to discrepancies in mother/child reports for child psychopathology. Divorces also occurred in some families.

Psychological support for both, children and family members are necessary. The need for a holistic approach in the assessment and treatment, including biofeedback techniques was pointed out.

Keywords: cystic fibrosis, chronic disease, psychology, holistic approach

Introduction

Cystic Fibrosis [CF] is a genetic disease that can be life threatening. It is considered to be the most common genetically based disease in white race population with an incidence of 1 in 1,500–2,500 live births, while in other races this ratio is 10 to 50 time lower. In Macedonia the incidence of CF is estimated to be 1 in 3,000 live births.

CF primarily affects the digestive system and the lungs, but can be systemic in nature as well. It develops because of a defective gene that forces mucus to build up in the lungs and other organs in a very thick layer. This mucus is difficult to process and it can begin to clog up airways so that it becomes difficult to breathe. In addition, many other complications such as chronic liver disease, diabetes, distal

intestinal obstruction, nasal polyps, rectal prolapse, pancreatitis, infertility, cardiac failure etc. may also occur.

In early childhood the meconium ileus, malnutrition, diarrhea and repeated respiratory difficulties and infections are the most common signs. Although the early diagnosis is crucial for the prognosis and life expectancy, the number of cystic fibrosis cases that are diagnosed by the age of 2 is only 5.75%.

The major diagnostic test is the sweat chloride determination (over 60 mmol/l), but after 1989 DNA testing is also used. The most frequent CF gene mutation is $\Delta F508$, present in about 70% of CF chromosomes worldwide, but altogether over 800 associated mutations have been described [34].

In our country are available genetic diagnosis as well as the antenatal carrier determination.

Medical therapy in CF is very extensive in order to maintain optimal health and to improve survival. Additionally, strong physical therapy together with balanced nutrition are very important.

All patients, as well as all family members must be educated and encouraged to participate in therapeutic procedures. Thus, patient's coping strategies and adaptation are of particular importance [12, 13, 15, 17, 19, 27].

Patients diagnosed with cystic fibrosis in the 1980s typically had a life expectancy of fewer than 20 years. Patients today can expect an average life expectancy of about 40 years. Babies born today with cystic fibrosis have an increased life expectancy from just four years to more than 30 years. Figure 1 shows changes in life expectancy starting from 1930 until nowadays.

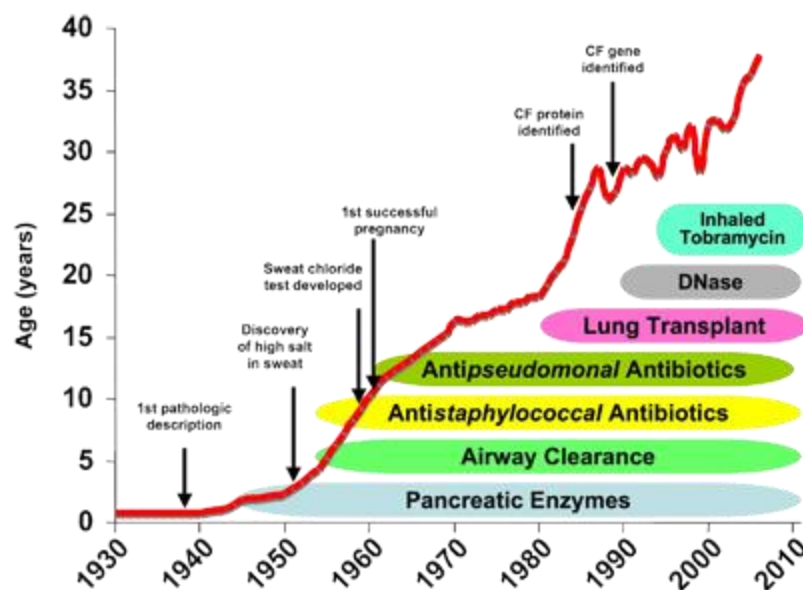


Figure 1 – Life expectancy in ages for CF patients

(Adapted From 2005 Annual Data Report to the Center Directors. Cystic Fibrosis Patient Registry, Bethesda)

Studies measuring psychological distress in individuals with cystic fibrosis have found high rates of depression and anxiety. Psychological symptoms in both individuals with CF and parent caregivers, have been associated with decreased lung function, lower body mass index, worse adherence, worse health-related quality of life, more frequent hospitalisations and increased healthcare costs [37]. However, Thomson et al [35] note that CF children ma-

nifest fewer depressive and dysthymic diagnoses than psychiatrically referred children.

Important psychosocial problems in CF children's adjustment comprise of: a) acceptance of the disease, including understanding and compliance, b) freedom from severe psychopathology, c) normal or age-appropriate personality functioning and d) age-appropriate functioning in school, with family and peers. Maladjusted children manifest excessive anxi-

ety, depression, school-related behavior problems or disciplinary problems at home [26, 36].

In the school period physical, intellectual and emotional changes are happening simultaneously. Peer group seems to be probably more important than ever, and it is normal to want to fit in, and not stand out as 'different'. Having CF, with all its challenges and time-consuming treatments can be a huge burden. Although patients could go through periods of depression, it must be remembered that they are not alone. Teens with CF report being depressed for many reasons such as: feeling physically unwell, being frustrated by the challenges of endless daily treatments, experiencing negative side effects from medications, missing major life events (sports, parties, concerts, proms) due to hospitalizations, and feeling different from their peers.

Children with CF may be teased or picked on at school because they can be underweight and small for their age, and might have a persistent cough. Taking tablets and capsules with meals and eating a different diet from classmates can also be embarrassing. Physiotherapy is time consuming, sometimes at the expense of a child's social life, although children with cystic fibrosis often find supportive friends who help with care and physiotherapy.

During teenage years there is a chance that children may neglect their physiotherapy and diet. Some people with CF experience delayed onset of puberty, which may cause anxiety or insecurity. Teenagers may need sympathetic treatment and counselling to help them deal with some of these issues.

Cystic fibrosis requires a level of special involvement from teachers, which could include consultations with parents or even practical help.

The important issue is related to parental coping and adaptation to CF disease in children. Many parents cope relatively well and do not manifest major psychopathological problems. But there are critical times during which parental functioning is strained, especially the role of mother [24]. Most of the family problems appear in the first year after the diagnosis of CF. Potential crises times for parents are cited in the following [32]:

- Diagnosis and explanation of the meaning of CF
- Future pregnancies
- Learning to cope with new demands, which may occur each time a new treatment is instigated
- First course of intravenous antibiotics and isolation of new bacteria from the sputum
- Problems with school and employment
- Increased need for antibiotics
- Change from pediatric to adult care
- Loss of responsibility such as allowing the children to perform their own treatment
- Decision about possible transplantation
- Deteriorating health of a sibling with CF, friend, or one's own child
- Death of sibling with CF, or own child
- Bereavement

Parents of CF children may express signs of depression, anxiety but also anger and hostility. Within a few years the family has more or less adjusted to the disease and equilibrium is restored, but still the process of stress and coping is dynamic and continues through the life span of the child and even after his death.

The aim of this study is a comparative evaluation of the personality profiles of school age children with cystic fibrosis with special attention to internalizing symptoms, and relating them to maladjustment and coping. Some controversial aspects of family functioning and child/mother discrepancies are also considered.

Subjects and methodology

The study comprises 25 CF children, mean age 13.13 ± 2.29 years (23 boys and only 2 girls), selected from total 60 actually treated children for CF. Children were examined in the period of improved health conditions (without superinfection, wheezing or gastrointestinal problems). The obtained results are compared with a control group of 25 healthy children of the same age, selected by random from primary schools.

The used psychological battery comprised Child Behavior Check List (CBCL), Kohs Design test, Eysenck Personality Questionnaire (EPQ), General Anxiety Scale (GASC), Emotional Profile Index (EPI), Human Values Test

(HVT) and two projective drawing tests – the drawing man test (Machover) and the drawing family test (Corman). Only for adolescents we applied Minnesota Multiphase Personality Inventory (MMPI-201).

CBCL [1] is designed to obtain the parent's descriptions of their own child behavior in a standardized format. There are 118 behavior problem items plus spaces for parents to write and score additional physical problems with no known medical cause. Two broadband groupings are in the focus: internalized and externalized. They reflect a distinction between fearful, inhibited, over controlled behavior and aggressive, antisocial, under controlled behavior. The profile can contribute to a formal diagnosis by showing the degree of child's deviance in behaviors that parents are more likely to observe than clinicians, as well as help to structure effective training. CBCL the most used test for selection of behavior problems in chronically ill children but the agreement between the scales and the mental diagnosis was shown to be moderate [5, 15].

Kohs Design Test [20, 38] presents a simple test for global intellectual functioning. The results are correlated with the logical thinking (analytical-synthetic performance) of the person. The standardization in Macedonia was made in the early 1978.

EPQ [14, 22] evaluates the four classical characteristics of the personality: N (level of emotional stability/neurosis); E (dimension of extraversion/introversion); P (psychotic behavior/psychopathy) and L (degree of dissimulation or social adaptability). Our previous experience with this psychometric test confirmed the validity, reliability and discriminativity of the obtained results, especially in preadolescents (10–12 years).

EPI [3] shows the emotional structure of the patients in correlation with their personal characteristics. The basic theoretical concept of the test is the hypothesis that the personality traits are the result of primary emotions and emotional states. The obtained emotional profile that indicates the main conflicting area of the person is defined through eight dimensions (related to eight respective emotional states): incorporation (acceptance), non-control (impulsiveness), self-protection (fear), deprivation

(sadness), opposition (refusal), aggressiveness (destruction) and reproduction (vivacity), while bias represents the scale for assessment of socially favorable answers.

GASC [33] is a simple questionnaire chosen to show the actual anxiety level, correlated with fears from different situations, persons and objects.

The drawings are used as projective tests in addition to other psychometric instruments [4, 11, 23]. Two projective techniques are used: Machover's analysis of the man drawing and Corman's analysis of the family drawing. Machover's man drawing test is selective for actual problems and conflict within the child himself; Corman's family drawing shows the social and intimate relation of the family members through the development of the patient as well as in the actual situation. Our previous experience in the psychological assessment of children with organic diseases through projective techniques is very positive [28, 29].

HVT [31] gives quick overview of the motivational structure of the personality related to the super-ego component. The hierarchical values are correlated to the real personal needs. It is also standard for assessment of the interplay of social situations and the self.

MMPI-201 [2, 16] contains ten clinical scales: Scale 1- Hypochondriasis scale which measures a person's perception and preoccupation with their health and health issues; Scale 2- the Depression scale measures a person's depressive symptoms level; Scale 3- the Hysteria scale measures the emotionality of a person; Scale 4- the Psychopathic Deviate scale measures a person's need for control or their rebellion against control; Scale 5- Paranoia scale measures a person's inability to trust; Scale 6- the Psych asthenia scale measures a person's anxiety levels and tendencies for somatization and obsession; Scale 7- the Schizophrenia scale measures a person's unusual/odd cognitive, perceptual, and emotional experiences, and Scale 10- the Mania scale measures a person's energy, euphoria or hyperactivity.

The three scales L, F and K are validity scales and measure the readiness of the responders to this kind of examination. The L

scale refers to rigidity or naiveté of responder's approach to the test material; the F scale refers to confused thinking/ lack of understanding the questions or malingering; the K scale refers to responses chosen to be socially acceptable.

Raw scores on the scales are transformed into a standardized metric known as T-scores (Mean or Average equals 50, Standard Deviation equals 10), making interpretation easier for clinicians. Before the analysis of clinical scales, some criteria should be satisfied: L and K scales must be with the score ≤ 70 and F scale ≤ 80 . A significant advantage of the MMPI over other self-report and observer rating scales is that it provides valid and reliable estimates of response bias.

This type of psychometric battery was chosen to obtain the global intellectual, emotional, behavioral and social functioning of CF children.

Results

The global intellectual functioning of CF children is evaluated with Kohs Block-Design test. The obtained mean score is $IQ = 104 \pm$

32.78 which means that children had normal intellectual level.

CBCL obtained from mothers showed 'normal' profile for the children's age (Figure 2). However, three aspects of behavioral problems are more expressed: aggression, depression and compulsivity, still below the 65th percentile (normal T-scores).

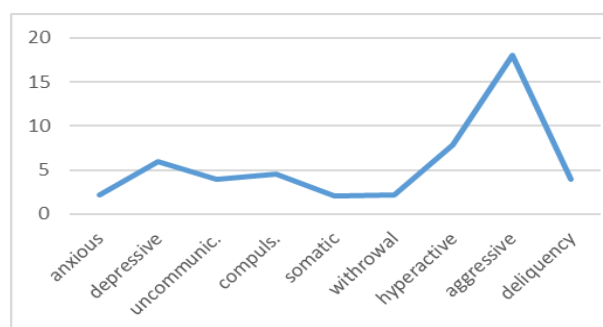


Figure 2 – CBCL profile for CF children

The results obtained for EPQ in CF patients compared with the control group are presented on Table 1.

Table 1

EPQ in patients with CF and control group

Group	P	E	N	L
CF	6.67 ± 2.90	15.91 ± 2.54	11.67 ± 4.23	15.0 ± 3.81
Control	11.87 ± 6.23	13.16 ± 5.75	13.84 ± 5.31	12.64 ± 4.62
Student t-test	$t = 2.87$ $p < 0.05^*$	$t = 1.66$ $p > 0.05$	$t = 1.18$ $P > 0.05$	$t = 1.45$ $p > 0.05$

Generally, patients with CF are similar in scores obtained for extroversion, neuroticism and lie dimension of EPQ with the control group. Only P scores are statistically lower than in healthy children, which corresponds to lower psychopathological traits.

The score obtained for GASC is $M = 17.17 \pm 11.69$ (out of total 35), which corresponds to the moderate degree of actual anxiety. The large standard deviation is related to large differences in the level of anxiety between patients. For example, two of the examined children manifested very high actual anxiety (obtained scores were 32 and 33 respectively); the reason was presumed to be the socioeconomic deficiencies in the families.

As it is well known, the treatment and the diet of CF children are quite expensive, so that in a situation of unemployment the procedure may be compromised, influencing malnutrition and emotional instability. However, generally, chronically ill children are overprotected, in attempt to satisfy most of their needs and wishes.

The results obtained for the Emotional Profile Index (Figure 3) showed high bias scores related to dissimulation. Incorporation and impulsivity are pretty high, which is in accordance with the results obtained with other tests. The scores obtained for aggression and depression are also accentuated, which corresponds to the insecurity related to the illness.

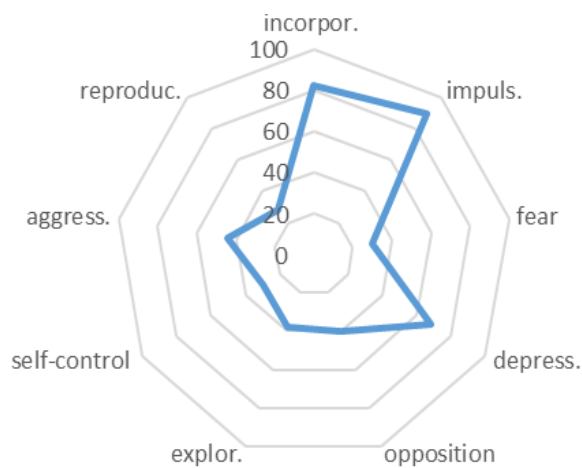


Figure 3 – EPI for CF children

MMPI-201 is applied only in adolescents (mean age 17.5 ± 2.6 years). Figure 4 shows MMPI profiles for girls and boys. The so called ‘neurotic’ profile (Hs-D-Hy), as it can be seen, is more accentuated in boys. Girls showed peak on Hy which can be interpreted as accentuated tendencies for conversion reactions.

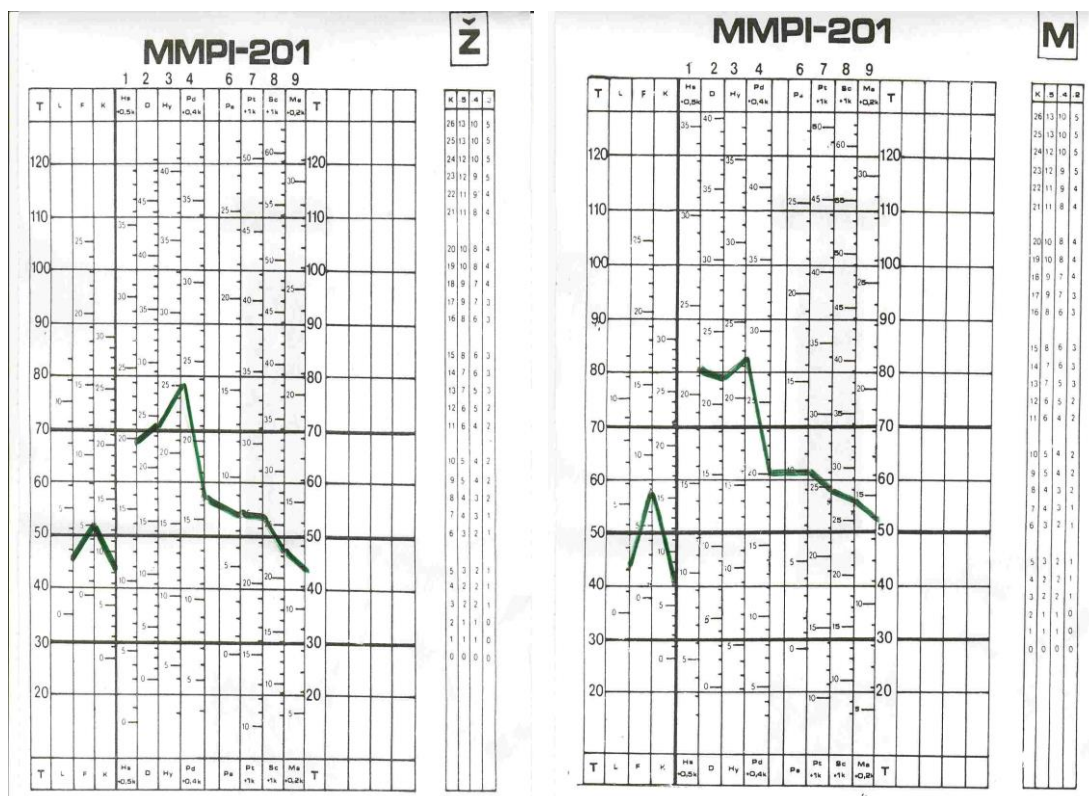


Figure 4 – MMPI profiles for girls and boys with CF

The drawings (Machover and Corman) obtained from CF children do not differ in general from those obtained from the control group. Good family functioning, the interrelationship between family members as well as the identity of the patients are interpreted as ‘normal’. In three drawings obtained, the figures with open arms could be related to an accentuated need for protection and love.

Finally, all children fulfil Human Values Rank [31]. HVR obtained from CF children was very interesting. As it can be seen on Figure 5, the main value for children is good health, which is clearly understandable. The high values given to the friendship and love express the need of support, and the following – freedom is stressed as necessary for living: these children need a feeling of freedom, the possibility to act and make decisions. Personal

happiness is also ranked high in the human values, related to self-development. The values quoted are generally highly ranked in adolescents and students, so that the obtained results could be interpreted as the earlier mental matu-

ration of CF children. The low value given to beauty, professional success, power and comfort in life could be related to low self-esteem and disappointment.

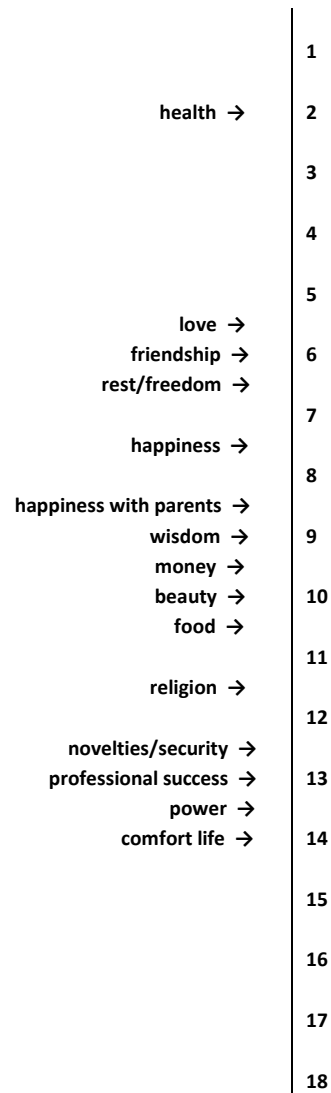


Figure 5 – Human Values Rank obtained for CF children

Discussion and Conclusions

The results obtained in our evaluation showed the normal intellectual functioning of CF children, which corresponds to the findings of other authors. In spite to chronic hypoxia, significant deficits in cognitive performance were not manifested. The obtained scores correlate to school achievement, and in spite of the frequent absenteeism, CF children are good pupils. Moreover, some psychopathological problems happen to be even less frequent than in healthy children (results obtained for EPQ).

Thomson et al. [35] reported that CF children have higher internalized scores on a child behavior checklist and experience distress, anxiety and depression, albeit not more than non-chronically ill children. However, from our test results, interviews with parents and the observation of children, we could generally conclude that the behavior of CF children in our study appeared to be within the normal range for the age. Only two children manifested psychological problems. One of them manifested a depressive reaction in his 17th year of

age, after his mother's and grandmother's deaths. This boy also manifested staturponderal deficit and sexual retardation. He has not adjusted to all therapeutic procedures for CF. Another boy, 14 years old, also with staturponderal deficit, manifested emotional immaturity and sado-masochistic attitude toward his mother. This boy's scores for aggressiveness were very high. Generally, the results obtained showed that CF children have relatively high cognitive skills, they are moderate extraverts, do not manifest major psychopathological behavior and they are not significantly anxious. This corresponds to Blair's [5] finding that most patients with CF are in robust psychological health.

The unexpected good psychological results could be explained by the fact that CF children accept the real situation and express vivacity, but the deep feelings of fear demand from them high self-control and resistance.

Most problems arise in the period of puberty and adolescence. The dysthymic feelings and fear causing accentuated self-control and self-defense are frequently present. Disturbed self-image, delayed sexual characteristics, staturponderal deficit, insecurity about the long-term prognosis are factors inducing behavioral and emotional problems in adolescents CF patients. None of our patients showed any sentimental relationship with the opposite sex, confirming the previous findings about the avoidance of close relationships with the opposite sex in adolescence [17–18].

All the families were well informed about the specificities of the disease. In general, they had no significant problems concerning normal family functioning. But, in three families divorce was noticed in the period of 1–2 years after the diagnosis, while in two the mothers died (from suicide and cancer, respectively). The poor economic situation is the biggest problem in some families.

As demonstrated in many studies like our own, the main psychological problems in the families are related to the mothers. The feelings of guilt, the everyday pressure related to nurture, medication and drainage procedures, the uncertainty of the future, were factors which influenced the mother's mental stability. In addition, the differences between the aggressive-

ness expressed in patient self-evaluation and the opinion of mothers have been noted. Canning [6–8, 10] also concluded that a discrepancy between parent and child reports concerning child psychiatric problems existed. This was also noted by Canning [9] where maternal distress was correlated with the number of disorders identified by mother, but not with those identified by child. In our everyday experience fathers are rarely present during control/hospitalizations. In some families we did not have any contact with the father.

Parental coping with the disease appeared to be problematic, which corresponds with the findings of other authors [21, 24, 32]. Our results also agreed with Eddy's [13] concerning the agreement between parents associated with problems in compliance with treatment, which have in adverse impact on the disease and health status of the child with CF.

We introduced the psychological assessment and support of CF children and their families with the general therapeutic procedures. Psychological interventions varied depending on the type of problem presented and the environmental context in which the child resides. Cognitive and behavioral treatment, combined with biofeedback modalities for relaxation were used, and have shown to be quite efficient [30]. Of course, parents and other family members were motivated to encourage the treatment. In our experience, the more frequent psychological problems during therapy were related to the child's adaptation and coping, especially in the period of puberty and adolescence, together with adherence to the medical regime and feeding, as well as parental coping linked to family dysfunction.

However, the main problems arise during the transfer of patients from pediatric to adult medical institution. Neither medical staff nor patients are satisfied to this transfer which is indispensable.

We can conclude that the multidimensional approach in the diagnosis and treatment of CF is 'condition sine qua non' [25]. Mental health professionals must be involved in the team.

The essential responsibilities of a psychologist working in a CF team are: (a) evaluating the psychological effects of living with CF

within the team, (b) undertaking comprehensive assessment and intervention when emotional, behavioural and psychological difficulties arise, (c) integrated post-diagnosis and annual reviews (comprising of assessment, screening and support), either face-to-face (which is preferable), and/or utilising psychometrically sound measures, (d) assessing the patient's and family's psychological resources, (e) providing support and where necessary, appropriate psychological intervention before and after the possible lung transplantation, and (f) actively participating in transition programmes (to high school and adult services) if these programmes exist or try to establish them if they do not.

REFERENCES

- Achenbach TM. Manual for the child behavior checklist/ 4–18 and 1991 Profile, Burlington, VT; University of Vermont, Department of Psychiatry, 1991.
- Arbisi P., Butcher JN. Relationship between personality and health symptoms: Use of the MMPI-2 in medical assessments. *International Journal of Clinical and Health Psychology*, 2004; 4 (3): 571–595.
- Baskovac-Milinkovic A, Bele-Potocnik Z. PIE, Profil Indeks Emocija, Manual, Ljubljana, Zavod za produktivnost dela, Centar za psihodijagnosticka sretstva, 1983.
- Biedma C. D'Alfonco P. Le langage du dessin, Delachaux et Nestle AS, 1955.
- Blair C, Cull A, Freeman CP. Psychosocial functioning of young adults with cystic fibrosis and their families. *Thorax*, 1994; 49: 798–802.
- Canning EH, Kelleher K. Performance of screening tools for mental health problems in chronically ill children. *Arch Pediatr Adolesc Med*, 1994; 148: 272–278.
- Canning EH, Hanser SB, Shade KA, Boyce WT. Mental disorders in chronically ill children: parent-child discrepancy and physician identification, *Pediatrics*, 1992; 90: 692–696.
- Canning EH. Mental disorder in chronically ill children: case identification and parent-child discrepancy. *Psychosom Med*. 1994; 56: 104–108.
- Canning EH, Hanser SB, Shade KA, Boyce WT. Maternal distress and discrepancy in reports of psychopathology in chronically ill children. *Psychosomatics*. 1993; 34: 506–511.
- Canning EH, Kelleher K. Performance of screening tools for mental health problems in chronically ill children. *Arch Pediatr Adolesc Med*. 1994; 148: 272–278.
- Corman L. Le test du dessin de famille. Presses Universitaires de France, 1977.
- Drotar D. Psychological perspective in chronic childhood illness. *J of Pediatr Psychol*. 1981; 3: 211–228.
- Eddy ME, Carter BD, Kronenberger WG, Conradsen S, Eid NS. Parent relationships and compliance in cystic fibrosis. *J Pediatr Health Care*. 1998; 12: 196–202.
- Eysenck HJ, Eysenck SBJ. Manual of the Eysenck Personality Questionnaire, London, Holder and Stoughton, 1975.
- Götz I, Götz M. Cystic fibrosis: psychological issues. *Paediatr Respir Rev*. 2000 Jun; 1(2): 121–7.
- Hathaway SR, McKinley JC. The Minnesota Multiphasic Personality Schedule. 1942, Minneapolis, MN.
- Harris ES, Canning RD, Keleher KJ. A comparison of measures of adjustment, symptoms, and impairment among children with chronic medical condition. *J Am Acad Child Adolesc Psychiatry*. 1996; 35: 1025–1032.
- Johannesson M, Carlson M, Brucefors AB, Hjelte L. Cystic fibrosis through a female perspective: psychosocial issues and information concerning puberty and motherhood. *Parent Educ Couns*. 1998; 34: 115–123.
- Kazek AE. The social context of coping with childhood chronic illness: Family systems and social support. *Stress and coping in child health (PP 262–278)* In AM LaCreca, LI Siegel, JI Walander and CE Walker (Eds), New York; Guilford, 1992.
- Kohs SC. Intelligence measurement; a psychological and statistical study based upon the block- Design Test, The Macmillian Co., New York, 1923.
- Kucia C, Drotar D et al. Home observation of family interaction and childhood adjustment to cystic fibrosis. *J of Pediatr Psychol*. 1979; 2: 189–195.
- Lojk L. Eysenck Personality Inventory, Manual, Ljubljana, Zavod za produktivnost dela, Centar za psihodijagnosticka sredstva, 1979.
- Machover K. Personality projection in the drawing of the human figure, Charles Thomas Springfield, 1949.
- Mullins LL, Olson RA, Reyes S, Bernardy A, Huszti HC, Volk RJ. An assessment of risk-resistance factors in the adaptation of mothers of children with cystic fibrosis. *J of Pediatr Psychol*. 1991; 16: 701–715.
- Nobili RM, Duff A, Ullrich G, Smrekar U, Havermans T, Bryonf M, Borawska-Kowalczyk U, Malmborgh MS. Guiding principles on how to manage relevant psychological aspects within a CF team: Interdisciplinary approaches. *Journal of Cystic Fibrosis*, 10, Suppl 2 (2011) S45–S52.
- Olson RA, Mullins JB, Chaney JM. Pediatric psychology, Allin & Bacon, 1994.
- Pfeffer PE, Pfeffer JM, Hodson ME. The psychosocial and psychiatric side of cystic fibrosis in adolescents and adults, *Cystic fibrosis*, 2003; 2 (2): 61–68.
- Pop-Jordanova N, Boskovska V, Avramovska V. Psychosomatic assessment of preadolescents with

- migraine-like headache. *Paediatr Croat.* 1998; 42: 33–37.
29. Pop-Jordanova N. Drawings as a projective test in somatic ill children, *EARA, Lausanne* 70 (p1–12), 1994.
 30. Pop-Jordanova N. Biofeedback modalities in children and adolescents, *New Research on Biofeedback*, 2005, Chapter IV, Nova Biomedical books, New York.
 31. Pogacnik VLV. Human values test, Manual, Ljubljana, *Zavod za produktivnost dela, Centar za psihodijagnostična sredstva*, 1988.
 32. Quittner AL, DiGirolamo AM, Michel M, Eigen H. Parental response to cystic fibrosis: A contextual analysis of the diagnosis phase. *Journal of Pediatric Psychology*, 1992; 17: 687–704.
 33. Sarason IG, Johnson JH, Siegel JM. Assessing the impact of life changes: Development Of the life experiences survey. *J Consult Clin Psychol*, 1978; 46: 932–946.
 34. Shale D. Cystic fibrosis, *BMJ Publishing Group*, 1996.
 35. Thomson RJ, Hodhes K, Hamlen KW. A Matched comparison of adjustment in children with cystic fibrosis and psychiatrically referred and non-referred children. *J of Pediatr Psychol*, 1990; 15: 745–759.
 36. Tropauer A, Franz MN, Diggard VW. Psychological aspects of the care of children with cystic fibrosis. In: Moss RH. *Coping with chronic illness*, Plenum Publishing Corporation, 1977.
 37. Whyte D. A family nursing approach to the care of a child with chronic illness. *J of Advanced Nursing*, 1992; 17: 317–327
 38. Zajec M, Bela-Potocnik Z. *Kosov test*, Ljubljana, *Zavod za produktivnost dela, Centar za psihodijagnostična sredstva*, 1981.

Резиме

ЕМОЦИОНАЛНОТО ЗДРАВЈЕ КАЈ ДЕЦА И АДОЛЕСЦЕНТИ СО ЦИСТИЧНА ФИБРОЗА

Нада Поп-Јорданова¹, Анета Демердиева²

¹ Македонска академија на науките и уметностите, Скопје, Р. Македонија

² Ацибадем Систина, Скопје, Р. Македонија

Иако модерните терапевтски процедури значително го подобрија преживувањето и квалитетот на живот на децата со цистична фиброза,

релевантните психолошки аспекти, сепак, се инфуфициентни, слично како и кај другите хронични болести.

Цел на ова истражување беше да се проценат емоционалното здравје: психолошките карактеристики и приспособеноста на ЦФ-децата, како и справувањето на нивните семејства.

Студијата опфаќа 25 ЦФ-деца, средна возраст 13.13 ± 2.29 години (23 машки и само две девојчиња), избрани од вкупно 60 актуелно лекувани деца со ЦФ. Децата се испитувани во период на подобрена здравствена состојба (без суперинфекција, отежнато дишење или гастроинтестинални проблеми). Добиените резултати се споредени со контролна група од 25 здрави деца на иста возраст, избрани случајно од основните училишта.

Користените психометриски инструменти беа: Косов тест, Детска чек-листа на поведение, Ајзенков прашалник за личност, Општа скала на анксиозност, Емоционален профил на личност, ММР-201 и Хуман тест на вредности, заедно со два проективни теста на цртежи (Махверова и Корманова).

Неочекувано добрите психолошки резултати добиени со психометриските инструменти можат да се објаснат со фактот дека ЦФ-пациентите ја прифаќаат реалната состојба и манифестираат жилавост. Сепак, нивните длабоки чувства на страв кај нив наметнуваат високо ниво на самоконтрола и отпор. Добиените резултати од СВСЛ ги прикажуваат ЦФ-децата како незрели, со нагласена агресивност во меѓучовечките односи. Најбитен проблем е доцнењето на пубертетските промени, што води до мало самопочитување.

Генерално, членовите на семејството релативно добро се справуваат со болеста кај децата, и покрај разликите во извештаите помеѓу мајките и децата за постоење на психопатологија. Во некои семејства постојат разводи.

Психолошката поддршка е неопходна за обете страни, децата и членовите на семејството. Нагласено е дека е неопходен холистичен приод во процената и лекувањето, вклучително и користење на биофидбек-техники.

Клучни зборови: цистична фиброза, хронична болест, психологија, холистичен приод