V. PSYCHOLOGY

PSYCHOLOGICAL ASPECTS OF LIFE QUALITY AT CHILDREN AND TEENAGERS WITH CYSTIC FIBROSIS

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Summary

At the Caucasians the most found inmate disease is cystic fibrosis (CF). It stands as the most feared enemy for patients and their parents. The CF patient's life-style is significantly affected.

After some several researches on CF youngsters, CMVT's team revealed some emotional and behavioural anomalies.

The family factors do have a big time influence as regarding the psychological adaptability to the CF suffering infant.

Argument

At the Caucasians the most found inmate disease is CF, mainly revealed in childhood.
Therefore it stands as a major concern of paediatricians even if not only-causing interests also for general pathology or several other specialised disciples.

This malady is a constant challenge for the scientist in the field of genetic, physiologic and biochemistry researches. For a practician M.D., CF is a painfully but usefully expertise. But it stands as the most feared enemy for patients and their relatives.

For those who suffer and for their families the struggle for surviving remains in a first tempo, even if there have been achieved huge progresses regarding the research and secrets of this type of disease.

1. General considerations

1.1. About Life –Quality concept

A wide-accepted definition is given by Flanagan: "generally spoken, Life-Quality is seem as the individual satisfaction generated by life itself or the joy of living given by the fields that a person puts as important".(I. B. Iamandescu, 2002, p.126)(3).But as time flew by, the noun developed but still got separated from the now-days concept of HRQL (Health Related Quality of Life).

I. B. Iamandescu and B.L. Plozza stated that HRQL is "the satisfaction given by life aspects that influence or get influenced by health"(2002,p.126)(3).They are trying to assess and to correlate the variables of health with the one's who's health may be affected by a particular disease. In HRQL concept are included aspects like: disease's influences onto bio-psycho-social aspects of health (in fact, induced influences on physical, social, psychological and emotional or cognitive factors), symptoms, own perceptions on your own health-status and general points of view about Life Quality.

The same authors do mention the most frequent indicators of the HRQL's concept:

Functionality:

-Physical functionality (ability in realising a wide range of physical activities such as walking, staircase climbing and sports);

-Role functionality (limited mainly due to physical disabilities or health status);

-Social functionality (that is shrinking the range of usual social behaviours or habits-meeting friends, group meetings).

The state of wealth:

-Mentally sane (induces various emotional states, depressions,anxieties);

-Vitality (own energetic tonus);

-Physical Pain (ability to sense pain or aches).

Own assessment of health:

-General own assessment of health condition;

-Significant changes of health during last 12 months.

Non-medical issues:

-Environmental issues (regarding urban environment);

-Social and human factors (social life management at it's various levels, the quality and size of interpersonal relationships).

Also, here is to mention that the patient's personality induces significant variations of all these factors, and mainly on his own, personal assessment ability.

1.2. Psychological perspective

1.2.1. Psycho-behavioural changes induced by sickness

I. B. Iamandescu (3) did underlined that the chronic patient's life-style is significantly affected by all hygienically-dietetically privations, drug's secondary effects and, mainly by the "hurt-feelings". These inflicts his personality as accepting this new social status of a "sick-man", with wide implications in his family and socio-professional life. Therefore, modern medicine science has to converge it's goals not only into optimising therapeutically means, but also in assuring a life quality for the affected, as much as possible as similar to the healthy one's.

As B. Luban-Plozza and I.B. Iamandescu (2002)(3) told, even sick-adults tend to regress their affective-behavioural consciousness, even from the very start of the illness, not to mention hereby the affection-seeking dependence or vulnerability of a youngster when sick, as been much more present.

Behavioural main features of a sick person

- Selfishness and excessive caprice (that may even lead in terrorising it's own family environment or medical one, due to shrinking the area of interest only to illness);
- Dependency, not only to medical staff but on environment, too;
- Predominancy in some emotional processes of affective (such as crying or anger);
- Aggressiveness, even if in a latent state (like criticising the care-takers) or in a obvious way;
- Fear/anxiety-as a response to illness, medical care, due to negative feedback about healing perspectives, that may overestimate latent fears;
- Depression-seen as fatigability, lack of interest, lack of eating-appetite, insomnia or hipersomnia;
- Dissimulated depressive state-revealed through some unspecific physical symptoms.

After some several researches on CF youngsters, our team revealed the next emotional/behavioural anomalies (on a reverse frequency average):

57%-attachment disorders;
45%-affective immaturity;
35%-anxiety;
35%-obvious aggressively;
35%-negativeness;
35%-iritability;
35%-emotional disorders;
10%-latent aggressively
10%-emotive lability;
10%-hostile attitudes;
10%-learning disorders;
10%-inhibition.

1.2.2. The urge on a psychological approach to chronic patients

The main objective of the entire psychological analysis should be focused on the patient, considering in any case factors as his psycho-behavioural problems and changes and his expectations (B.L.Plozza and I.B.Iamandescu)(3).

In the established bond between the patient and therapist, it's quite important to unleash emotional stress, which will lead to a significant decrease of stress. Two facts could lead in time to decrease or even to disappearance of psycho-behavioural ill-induced changes: depicting psychological problems and establishing a dialogue and a strong bond.

Achievable objectives through a long lasting psychological assessment should in any case include: minimising aggressively, anxiety and depressions, even extinction them, replacing a nocive behaviour with a well-balanced one, and inducing a proper attitude on illness.

2. Case reports

We used the following methods and tests while investigating our subjects:

Methods:

-Direct observations on subject's behaviour;

-Clinical interview-made for gaining data and understanding the psychological profile of the subject-"focusing the approach on his feelings, as a revealed in the pre-established bond from the interview"(I.Dafinoiu,2002)(2);

-Anamnesis-usefully in collecting data about important events and possible clinical aspects of the patient.

Tests:

-Machover's test;

-The tree test;

-The family test;

-Raven test.

To every patient we did realised a psychological profile, focused mainly on life-quality factors vs. health: physical functionality, social functionality and environment.

Case 1: I.P., male, 5 years old

Anamnesis:

1. Physical and psychological development.

Child born at 9 months of pregnancy, with 3,4 kg weight and 51 cm height. Is the second sibling. Was diagnosed with CF at 3 months, in another paediatric clinic, is listed at CF Centre of Timişoara since 28.02.2002.Isn't suffering of any cerebral diseases.

2. Family scene.

I.P. has a harmonious family, is beloved and well protected. Has a elder sister.

3. Educational-professional record.

Due to his age and health conditions, I.P. hadn't follow any institution.

4. Social system network.

Being pretty spoiled, he's main attraction of his family's interests. His playground mates are his sister and the kid's of family's friends.

5. Psychosomatic illness record.

Has not.

6. Present clinical record

Diagnose: CF, complete form, ΔF508, complicated.

Psychological profile

I.P. has an overrated attachment towards his mother-while having to baby sit him 24 hours-a-day. Even while playing I.P. has to assure himself that mom is close, by seeking her all the time. This may be an anxiety sign. The kid is afraid being alone, is scared of being dropped-he doesn't understand his sickness, he's afraid of injections, he dislikes drug's taste and has bad feeding habits.

I.P. is in an specific development stage, he just realised he's different and wishes to show this fact to others. Being shy he needs quite some time to adapt to a new environment. But then he gets talkative. If he feels accepted and beloved, he becomes confident and open to share all he knows: the poems he knows, he plays. When he's not feeling well, he gets irritable and aggressive: throwing toys, rejects food saucer and hits he's mom.

Very sensitive and receptive at all the reactions from people from around, he takes on some of his mom's anxiety. His mom, noticing the digital hypocratism didn't understand the facts and got worried, thinking that her kid will become somewhat freaky. Her worries were transferred to the kid-who got also tensed and worried. The kid got pretty quiet and calm, after the facts were explained to him.

The psychical and senso-mothrical state of development of I.P. is specific to his age. The kid is visiting CMV from time to time, because of his actual well status.

Case 2: I.I., female, 9 years old

Anamnesis:

1. Physical and psychological development

Child born at the age of nine months at 2,5 kg weight, Apgar index 8.Diagnosed at the age of 2, is being held under CMVT supervision since 4th march 1996. Has not been suffering of any cerebral diseases.

2. Family scene

I.I. is the 5th sibling in her family. There's a special team spirit in the family- all brothers and sisters do take care of each other, and all this around mom-the core of the I.I.'s family.

3. Educational-professional record.

I.I. is on a regular basis attending school, even if frequently interrupted-due to several nursing periods.

4. Social system network.

Beyond normal brotherhood ties, she has usual friendship relations with her cousins.

5. Psychosomatic illness record.

Has not.

6. Present clinical record.

Diagnose: CF-complete clinical form.

Psychological profile.

Even if someone may think about I.I. as being moody and fanciful, in fact she's anxious and mother-dependant (nursed together with her).She may show from time to time signs of sociability and adaptability, but critical episodes do affect strongly her physical functionality-she feel s fatigue, tired, with a low energetic tonus-and her emotive status- as being sad and bad-tempered.

Her affective evolution did not follow it's optimal course, I.I. has an 6 years old behaviour. The fact is also due to her mother-due to her dual attitude towards punishment-motivation-she even over spoils her, or mistreats her: by neglecting her intentionally or by telling her that she won't be loved if she isn't well-behaved.

The psychological interference was realised through playing therapy. The main objectives where set in minimising tensions and irritability as well as concealing mom in adopting a proper and adequate attitude towards her child-a mother-like, protective attitude, avoiding overrated spoiling and replacing punishments with explanations about the child's mistakes.

The now-days psychological status of I.I. is still oscillatory due to her mother's emotively and anxiety, even if medically speaking the disease is under control and care.

Case 3: K.B., male, 13 years old

Anamnesis

1. Physical and psychological development.

Born at the age of 9 months of pregnancy, at 3 kg weight and 51 cm height, breast feted till 3 months. Was CF diagnosed at the age of 3 months and recorded at Târgu-Mureş Paediatric Clinic;

CMVT recorded him in 25/10/02.Hasn't been suffering of any cerebral diseases.

2. Family scene.

K.B. is single to his parents, well beloved and protected. This family ties are unite and strong-bonded, all of his relatives are interested by him, and his some age cousins are his best friends.

3. Educational-professional record.

He attended regularly kindergarten and school, but now-a-days-because of frequent and extended hospital care-his mother coaches him. K. B. doesn't speak Romanian (even if he knows only a few words) but he comprehends some, he speaks natively Hungarian and learns English.

4. Social system network.

Beside his cousins, he doesn't have many friends, but he has some play mates. He is willing to establish relationships with people around him.

5. Psychosomatic illness record.

Has not.

6. Present clinical record.

Diagnose: CF, complete clinical form, homo-zygote ΔF508, classical phenotype, with complications.

Psychological profile.

We were asked to assess K.B. in order to determine his IQ, because he seemed as not been able to comprehend any of what it was explained to him. His apathy state seemed unchangeable, nor his mother couldn't interfering in Hungarian, not to mention the fact that he don't understands Romanian too. The MD that asked CMVT for assistance did presumed presence of an anxious-phobic disorder, facts that were partially confirmed.

We can state-after examining K.B.-that he has a minimal intelligence, but this can be seen as quite regular, not as being retarded. Even he is hypersensitive, he benefits of his family's support, and regularly he feels as being loved and protected. Pretty helpfully in his struggle comes his stabile and friendly familial environment.

K.B. is a quite skilled drawer, and he proves even to be creative if he can express his own feelings He is able to conceive easily both friendly places and events.

To his health disorders do come some growing-up problems, and, therefore there may appear moments when he acts as easily annoyed or sometimes as trying to act explicit, by using improper attitudes. His anxiety is strongly related to his disease. He gets easily tensed and scared when he doesn't comprehend what happens, or when he doesn't get explanations about the sense of drugs use or when over-examineted. He has also a darkness phobia-as his mother told us.

Direct communication is somewhat difficult, as being used mom's translations and explanations. We used non-verbal gestures, simple words that could reach his own understanding
(at least partially) and to dilute some of his fears.

He is attending all medical prescriptions, and well participating in prescript therapy procedures, including physical-therapies ones, and now he looks emotionally well balanced.

Case 4: B.C., male, 14 years old

Anamnesis:

1. Physical and psychological development.

Born at 9 months of pregnancy, at 2,9 kg weight, I.A.= 9, was breast fed till 3 months. Is been held under CMVT's supervision since 30th June 2000.Hasn't been suffering of any cerebral diseases.

2. Family scene.

B.C. is the only sibling, he is in the centre of his family's attention; his parents show some overrated attitude towards his education and in the same time some maximized protection.

3. Educational-professional record.

B.C. attends regular school classes with good and even very good marks and results. He has artistic skills: he's a good drawer, he sings and writes poems and tales.

4. Social system network.

He hasn't close friends, social relations of him are under strict parental control.

5. Psychosomatic illness record.

Has not.

6. Present clinical record.

Diagnose: CF, respiratory form.

Psychological profile.

B.C. even if he is an teenager, proves to be calm, obedient, hesitant and perfectionist. He tries to be best in all he does. Even his artistically area is a opportunity to reveal perfectionism: he is detail oriented, he re-draws parts of his drawings in order to improve them' he re-builds rhymes from his poems.

Generally, his entire behaviour reveals a pregnant anxiety-he feels a strong urge to control, in the deepest details, in order not to fail.He's quite a good observer and shows prudence when involved in non-familiar duties.

B.C.'s physical activities are minimal, he doesn't attend sports at school or any physic –therapeutically program, on a regular basis. Opposite to this he shows an intellect-oriented behaviour, B.C. needs to express personal values, his idealism, enthusiastic habits, he's ambitious and impressionable, but unable to get frustrated-facts which reveal a childish attitude.

At regular counselling meetings B.C.'s mother isn't a usual participant, and even so it has been observed that auto relaxing is the appropriate technique in dealing with his disease.

Conclusions about the CF subjects:

-As concerning Raven's test results-all subjects have a normal mental state.

-Their physical functioning might be temporary affected during severe seizures.

-Even if emotional and behavioural disorders are quite recurrent, they aren't considerable ones, while social functionality is recorded as been under acceptable levels.

-These is to be attested a proper life quality of those CF suffering subjects, due to proper medical care and their families involvement.

3. The parent-youngster/teenager-disease correlation

3.1. The interconnection parent-youngster-disease.

The family is a complex system. Here in, any interaction between it's compounds will affect the entire system.But the interference of a strong, sudden vector will daze the entire balance and stability of the interactional area, specific to a family. It is known that through a child birth there do occur significant changes between husbands-they get also a parent role. We can notice that the interaction between mother-child do influence the tie between husbands, but also the relations between the parents do influence the relations with the child. New siblings will also generate changes to family ties.But the discovery of a chronic disease of the child may be seen as a vector that will destroy irreversible the relational balance of a family.

Some chronically disease does alter the child for long periods of time-and even sometimes the entire life, fact that has serious consequences on his relations with mom, family, playmates or school colleagues, and generally speaking with the entire physic and social sphere. The malady does influence all stages of development, generating progress problems in cognitive or psychosocial fields. The effects may vary depending on the child's character, his family's psycho-support (especially from mom), the medical interferences, age or social assistance (C.Ciofu,1998 p.118) (1).

The basis of the complex human structure is designed in childhood. Starting at early ages the infant learns how to relate to others, observing as models his parents.If inter-human relations in his family are harmonious, the little child will gain a proper psychological basis, which will lead him among his entire life. This basis will also lead to a proper balance from his sub consciousness, also with influence on the emotional balance of his personality.

Unfortunately, both congenital chronic diseases and those from early childhood, do negatively influence inter-familial relations and the emotional balance of the child. Among this diseases with influence is CF.

The family factors do have a big time influence as regarding the psychological adaptability to the CF suffering infant.

Subsequent influential factors do include familial circumstances, such as: size, structure, socio-economic status, parent's health, attitude towards illness, communication among family members (I. Popa, Z. Popa and L. Pop, 1998)(5).

When we evaluate familial factors, independently from the illness stage, we mainly seek for:

1. CF's interference on the family.
2. Family's functionality towards illness.

Here can be evaluated the effect on the entire family, towards the parents, on brothers or on the ill-child himself.

M. E. Hodson and D.M. Geddes (4) studies do reveal that trauma's depth and length lead the parents to sacrifices, parents don't have any time or means for specific adult duties. It outcomes a lack of communication among family members, some sort of silence that leads to misunderstandings and family malfunctions. These are still a few studies done on CF ill person's brother's, even if in some cases, there was noticed some CF's acting from younger brothers in order to get a similar treatment (favourite) from the parents. Elder brothers are generally protective and helpfully. The attitude towards disease tends to change depending on sickness' stage. The care towards the patient is variable depending on the disease's stage.

Familial dysfunctions do affect negatively the behavioural and health's status of the CF's sick infant. There can be established a bond between bad functioning and the amount of behavioural problems of the CF's suffering child.

CMVT's practical experience revealed that:

- A big majority of parents react through a psycho-emotional blockage the very moment they get the diagnose. For a instance they can't comprehend what kind of disease they are dealing with, and they cannot react affectively in any manner.
- Immediately follows a stage of distinct confusion-they can't be certain if they understood properly what happens or if something bad happens to them.
- Some of them deny the facts that the illness will affect their sibling, and some of them even ask for some new medical analysis.
- As they realise explanations they get, they will react accordingly to their personality-some become excessively anxious, some get depressive, but there could be found parents who will try to keep up emotional balance not to induce additional fears to the ill infant. Also there had been found some cases in which one partner is blamed for the appearance of CF at their infant. We couldn't assess any cases of hostility towards medical personnel or towards medical sciences.
- Generally speaking the parents are open in offering to their sibling the entire support. There could be also found certain dysfunctional family entities wham's relational disorders significantly do influence the youngster.
- The most frequent caring parent are mothers. Many of them will institutionalise themselves only to comprehend in the best form how to care the youngster, therefore the compliance to care is high.

3.2. General advices for parents.

It is seen as mostly important the relatives' support (mainly the parent's support) both for the young CF sick child and for other chronic ill ones.

Therefore, here are some advices, such as:

♣ Not to highlight the illness state of the youngster, versus creating a proper environment for him to develop properly his own personality.

♣ Not to keep the youngster isolated from other same-aged kids, but to encourage him in developing friendship relations.

♣ Not to over spoil him, but also not to loose a proper authority towards him.

♣ To assign him age-proper duties, and to observe him discreetly.

♣ To listen him patiently when he needs to describe feelings or when he needs to confess.

♣ Not to give orders, but advices-and only at a proper time.

♣ Not to highlight failures, but to praise his achievements.

♣ To express an understanding attitude, and to express helping attitudes in overcoming difficult moments.

Statement and advice.

As we all agree, CF's suffering children are destiny's victims, and caring specialists shall contribute in helping them face their cruel destiny with a smile under their innocent eyes.

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