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PSYCHOLOGICAL AND SOCIAL PROBLEMS OF PATIENTS WITH MALIGNANT HAEMATOLOGICAL DISEASES

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Different psychological and social problems deteriorating patients' quality of life appear together with the prolongation of the duration of life. The aim of this study was their investigation and systematization. An inquiry proposed by the authors was used. It consisted of 5 groups of questions, referring to the type of behaviour at the time of information about the diagnosis as well as to patient's everyday functioning. Lack of realistic "internal picture of the disease", change in the hierarchy of values with loss of some and appearance of other new values, condensing the life events were found out. A change in the balance model before and after the disease towards increasing the interest for the body and the cares for it, as well as reduction of contacts outside the family were observed. A deterioration of social status was found out in 90 % of the patients. Important ways for overcoming the psychological and social problems in the patients with onco-haematological diseases were discussed.

Key-words: Oncologic haematology, psychology, sociology, psychosocial stress, adaptation

Different psychological and social problems deteriorating patients' quality of life appear together with the prolongation of the duration of life. Practically, patient's life problems begin in the "non-organized phase of the disease" soon after he has been informed or self informed about his diagnosis. Kubler-Ross has described 5 phases through which a patient may

pass after being informed of the diagnosis: 1. Refusal to accept the facts of his illness. Takes refuge in isolation. 2. Anger and opposition. 3. Negotiating phase (entreats to doctors in particular). 4. Depression. 5. Coming to terms with the outlook. Calm and worthy acceptance (1). The duration of the different phases differs a lot. That is why it is of particular importance for the psychologist observing the patients to evaluate the phase. In our country the above mentioned examination is being carried intuitively by non-educated in this aspect personnel - a doctor, treating the

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patient and a nurse. In the early phase of the disease the patient is unable to respond the expectations and many psychological, social and somatic problems appear. Balint points out that this phase of the disease is of particular significance for the future fate of the patient and the disease (2).

Very important for the psychological and social adaptation of the patients is the participation of the members of the family, who should be informed and educated about the characteristics of the disease, the type of treatment and the expected results from it. Attention must be pointed on: 1. Detailed information of the relatives. 2. Maximum possible mobilization of the available reserves of family members. 3. The detection of any anticipatory mourning either on the part of the patient, or on that of the family. 4. An offer of continued partnership with the family after the patient's death (3). Ensuring an optimal social status is of great importance for the preservation of the quality of life of oncological haematological patients. This is a prerequisite for overcoming the different additional psychosomatic disturbances such as sexual disorders, arterial hypertension, tachycardia, etc. as a result of long-lasting psychosocial stress (4).

Based on the critical situation of Bulgarian healthcare and in spite of that in this study we aimed at marking the main psychological and social problems of the patients with malignant haematological diseases appearing at the time of information about the diagnosis and under outpatient conditions.

MATERIAL AND METHODS

Twenty-three patients with different haematological malignancies were enrolled in the study. In order to exclude some age psychic disorder the upper age was limited to 55 years. The base for the psychological study was an inquiry proposed by us and including 5 groups of questions: I. About the diagnosis and the internal picture of the dis-II. About values: III. Life events during the last 5 years; IV. A balance model of positive psychotherapy before and after the disease, and V. Diseaserelated difficulties in everyday life. Social status was studied with the help of standard inquiry for sociological studies.

RESULTS AND DISCUSSION

The way of patients' getting informed about the diagnosis was the following: from the doctor treating the disease – in 57 % of the cases; "I heard doctors commenting" – in 9 %; by reading medical documentation and being informed by a member of the family – in 17 % each. According to their emotional reactions when learning about their diseases, the patients were divided into the following groups: 1. "I accepted everything normally, in cold blood, I did

not get frightened, I was prepared by the doctors about that" - 12 patients; 2. "I was astonished, shocked, the world around me collapsed" - 7 patients, and 3. "I retired into myself, I withdrew, money problem became essential" - 4 patients.

In the phase of information about the disease some patients suffered from non-human attitude by the medical staff and as a result of that the patients lost confidence in them and refused specialized treatment. Some patients demonstrated strongly expressed mechanisms of psychological defense **unch** as rejection (scotomization of the disease), pushing, rationalization, which prevents from the formation of a realistic internal picture of the disease **nd** the corresponding behaviour of ■vercoming. In our contingent the adequate reaction of the patients to the disease prevailed.

In all the patients the disease as a rule appeared to be an unifying factor for the family, even the extended family. The relatives gave courage to the patient and implemented some of his obligations. In some families reorganization included change in the place of living (house, town). All of them were lacking professional psychological help in spite of the fact that greater part of the patients confessed they were "totally psychically decompensated".

To a certain degree patients find psychological help in the physician curing the disease - an ally, support and all

expectations were pointed on him and his staff. In no patient did we find deviations toward non-traditional methods of controlling the disease - extrasensory people, paranormal effects, etc.

Four patients only answered the question "What was changed in your life?" that there were no changes. In the rest cases there were changes in four main directions: 1. Retiring from work; 2. Long hospital stay; 3. Reduction of the contacts, and 4. Change in the position among the surroundings, unpleasant feelings of regression linked with the disease, especially in the patients with higher social status.

A rearrangement of the hierarchy of values of the patients compared with the premorbid phase took place with two main tendencies: 1. Eight patients described 12 valuable things for them arranging these things according to their relative significance; 2. Fifteen patients suffered difficulties in listing more than 9 values. One of them could state only one - health. Summarizing Patients' answers to the inquiry the following factors embarrassed most their everyday life: 1. Overanxiety of the relatives, pity; 2. Shame ("As if I am very seriously ill and I am still alive"); 3. Fear ("How shall I feel tomorrow"); 4. Lack of perspective and ambitions, living "day for day"; 5. Poor outlook; 6. Feeling of no way out, lack of choice, doomed to failure: 7. Pain from chemotherapy and dependence from the latter; 8. Problems with transportation,

expected complications from chemotherapy.

All these difficulties had their psychological dimensions and needed professional intervention. The latter enabled the enrichment of the hierarchy of values and pointing patient's attention towards new aspects of existence. Condensing life events in negative aspect with greatest relative share of the disease was found. The latter was considered the most important negative event.

In 70 % of the patients inquired the balanced model showed a change before the illness the patients put accent on their job, business; after that exclusively on their bodies. In the rest 30 %, however, the distribution of energy before the illness was just the same as the above mentioned and after the illness it was directed towards "future". The patients inquired were from different towns of North-Eastern Bulgaria. All had families with one or two children. Ninety percent of them had retired from work with pension for disability. The rest ones were not working for a long time for medical treatment. The amount of money the patients with invalidity took as a pension is 35000 -45000 lv. Because of the lack of drugs in hospital pharmacies as well as their

deficiency in pharmacies, delivering them free of charge, greater part of the patients spent 50000 - 200000 lv. for treatment monthly. That money should be taken from family budget, relatives and sponsors (the latter very infrequently). The necessity of monthly treatment with average duration of 10 days deprived the patients to work even non-qualified labour on hour schedule in order to help family budget. Patients (especially men) confessed that they felt being burden for their relatives.

CONCLUSIONS

- 1. It is necessary to perform psychotherapeutic work with patients in order to enrich the hierarchy of values and focusing their attention on new aspects of life.
- 2. Close relations between patients and social workers are essential the latter being at disposal of the Clinics of Haematology in order to integrate the patients in society as soon as the diagnosis is established.
- 3. Changes in the status of the Clinics of Oncohaematology and amelioration of the living conditions for the patients, including the outpatients as well as inclusion in the staff a psychologist and a social worker are needed.

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Психологични и социални проблеми при болни от злокачествени кръвни заболявания

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Резюме: Успоредно с удължаване на преживяемостта при злокачествените кръвни заболявания възникват редица психологични и социални проблеми, влошаващи качеството на живот на болните. Цел на настоящата работа е те да бъдат проучени и систематизирани. Използвана е анкета, изработена от авторите, включваща 5 групи въпроси, които се отнасят до типа на преживяване при научаване на диагнозата и функциониране на пациентите в ежедневието. Установява се липса на реалистична "вътрешна картина на болестта", промяна в ценностната иерархия със загуба на едни и поява на нови ценности, отчита се сгъстяване на жизнени събития. Наблюдава се промяна в балансовия модел преди и след заболяването по посока на засилване интереса към тялото и грижите за него, както и намаляване на контактите извън семейството. Отчита се влошаване на социалното състояние при над 90% от болните. Обсъждат се основни мерки за преодоляване на психологичните и социални проблеми при пациенти с онкохематологични заболявания.

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