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DAMAR MƏNŞƏLİ DEMENSİYASI VƏ ALSHEYMER XƏSTƏLİYİ OLAN ŞƏXSLƏRƏ QULLUQ EDƏNLƏRİN PSİXOSOSİAL DEZADAPTASİYASI, HƏYAT KEYFİYYƏTİ VƏ SOSİAL FƏALİYYƏTİ

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Xülasə. *Məqalədə damar demensiyası və Alsheymer xəstəliyi olanlara qulluq edən şəxslərin psixososial desadaptasiyası, həyat keyfiyyəti və ictimai fəaliyyətinin öyrənilməsindən alınmış nəticələr şərh edilmişdir.*

Tədqiqata adı çəkilən xəstəliklərdən əziyyət çəkən şəxslərə qulluqla məşğul olan 103 nəfər cəlb edilmişdir. Qulluq edən şəxslərin himayəsində olan xəstələr xəstəliklərin Beynəlxalq Təsnifatının 10-cu versiyası üzrə F00-F01 diaqnozu qoyulmuş, psixiatrın dispanser müşahidəsində olan şəxslər olmuşdur. Damar demensiyası və Alsheymer xəstəlikləri olan xəstələrə qulluq edən şəxslərin şikayətlərinin ətraflı öyrənilməsi və statistik analizi əsasında onların fəaliyyətinin müxtəlif sahələri üzrə aşkar edilmiş funksional problemlərin ümumi "bankı" tərtib edilmiş, sonra isə bu funksional pozuntuların əks edildiyi ən mühüm dezadaptasiya istiqamətləri ayırd edilmişdir.

Tədqiqat nəticəsində aydınlaşdırılmışdır ki, müvafiq xəstələrə qulluq edən şəxslərin həyat keyfiyyətinin pisləşməsində əsas rolu psixososial dezadaptasiya oynayır. Onların öz işlərindən həzz almaması fəaliyyətlərinin çətinliyinin əsasını təşkil edir.

Açar sözlər: *psixososial dezadaptasiya, həyat keyfiyyəti, damar mənşəli demensiya, Alsheymer xəstəliyi*

Ключевые слова: *психосоциальная дезадаптация, качество жизни, сосудистая деменция, болезнь Альцгеймера*

Key words: *psychosocial maladjustment, quality of life, vascular dementia, Alzheimer's disease*

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PSYCHOSOCIAL MALADJUSTMENT, QUALITY OF LIFE AND SOCIAL FUNCTIONING OF CAREGIVERS OF PATIENTS WITH VASCULAR DEMENTIA AND ALZHEIMER'S DISEASE

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This article covers the issues of studying psychosocial maladjustment, quality of life and social functioning of caregivers of patients with vascular dementia and Alzheimer's disease.

The study involved 103 caregivers of patients with Alzheimer's disease or vascular dementia. Patients were diagnosed F00-F01 according to ICD-10 and were registered in a psychiatric dispensary. According to detailed study and statistical analysis of the caregivers' complaints, a general corpus of data on the identified performance problems in various spheres of activity was formed. The most important directions of maladjustment that reflect the great bulk of the identified functional disorders were identified.

According to the results of the study it was found that psychosocial maladjustment plays a decisive role in the deterioration of the quality of life in caregivers of patients with vascular dementia and Alzheimer's disease. Dissatisfaction with their own functioning in various areas reveals the leading sources of difficulties.

Epidemiological data indicate the considerable prevalence of Alzheimer's disease both throughout the world and in Ukraine. A significant number of patients with dementia, in particular Alzheimer's disease, in our country receive therapy at home and their relatives (caregivers) take care of them. The burden of caring for the patient falls entirely on the family due to the underdevelopment in our country of specialized services for the provision of specialized outpatient care. Caring for seriously ill relatives is not only an exhausting life situation, but also a constant reminding of the possibility of one's own death or illness. The progression of the disease leads to the need for round-the-clock observation and care of the patient, which causes a constant emotional stress and exhaustion of the caregivers, disruption of their adaptive mechanisms at the level of the body and personality [1,2,3].

Psychiatry has considered the problem of all kinds of states of psychosocial maladjustment for a long time. In particular, attempts were made to describe them in the form of the following categories: nostalgia, psych emotional stress syndrome, premorbid forms of emotional stress, mental maladjustment, psychosocial maladjustment, prenosological conditions, maladjustment or non-pathological neurotic manifestations.

In this context, the concept of a barrier to mental adaptation is extremely important. It is an individual functional-dynamic formation that prevents overstrain of the mechanisms of mental adaptation, which may result in the formation of a state of mental maladjustment and mental disorders, in particular neuroses.

The mental adaptation barrier is dynamic. It approaches the individual critical value in a state of mental stress. At the same time, a person uses all his reserve capabilities and in the case of a harmonious psychological attitude to a stressful situation sometimes becomes able to perform especially difficult activities without feeling anxiety, fear and confusion, which impede the most adaptive behavior [4,5].

But long-term and especially harsh tension of the functional activity of the adaptation barrier leads to its overstrain, which is manifested by the state of maladjustment [6,7]. If the pressure on the mental adaptation mechanisms increases and the reserve capabilities are exhausted, then there is a "tearing of the barrier" and the formation of borderline mental pathology [8].

Schematically, the process of maladjustment develops according to the principle of a “vicious circle”, where the trigger, as a rule, is a sudden change in living conditions or familiar environment, the presence of a stable psychotraumatic situation. In the future, maladjustment aggravates the existing mental and somatic disorders leading to even greater maladjustment and further functioning deviations. The literature describes in sufficient detail, in particular, numerous neurotic and psychosomatic symptoms accompanying psychosocial maladjustment [9]. With social maladjustment, we are talking about a violation of the process of social development of an individual, when there is a violation of both the functional and content side of socialization. In essence, this implies a person's social inadequacy, his inability to fulfill the usual role for his own status in society due to limited functionality. This can lead to a loss of the ability for independent existence, the establishment of social bonds, dependence on the help of others, and disruption of professional activity. When this condition protracts for a long time, there is a risk of emotional exhaustion: irritability, breakdowns, insomnia, psychosomatic diseases (arterial hypertension, coronary heart disease, obesity). In addition to clinical consequences, the prevalence is accompanied by significant negative socio-economic consequences for both the caregiver and society as a whole, significantly worsening the quality of life and the level of social functioning.

The aim of the study was to study psychosocial maladjustment, quality of life and social functioning of caregivers of patients with vascular dementia and Alzheimer's disease.

Material and methods. The study involved 103 caregivers who were caring for patients with Alzheimer's disease or vascular dementia. All caregivers sought advice from the staff of the Department of Psychiatry, Narcology and Medical Psychology of Poltava State Medical University and provided written informed consent to participate in the study. All patients who received the care of caregivers had an established diagnosis of F00-F01 according to ICD-10 and were under dispensary supervision in the Poltava region. 42 patients previously received inpatient treatment at the 7th department of the Public Institution, Poltava Regional Council "Regional center for psychiatric support".

To achieve the goal and implement the objectives of

this study, the following methods were used: information and analytical, clinical anamnestic, clinical and psychopathological, psych diagnostic, psychometric and statistical methods of mathematical processing of the received results.

Selected psychodiagnostic techniques supplemented clinical and psychopathological research and were used to obtain a quantitative assessment of clinical indicators.

1. To identify and measure the severity of psychosocial maladjustment in caregivers of patients with Alzheimer's disease or vascular dementia, the *"Scale for a comprehensive assessment of the degree of psychosocial maladjustment in different spheres"* was used according to Larysa O. Herasymenko, Rustam I. Isakov [10].
2. "Scales for assessing the quality of life" N. Mezzich, N. Cohen, M. Ruiperez, I. Lin, G. Yoon adapted by N.A. Maruta [11,12] was used to assess mental status and psychological state influenced by emotional, financial and social well-being. The quality of life is a state of an individual in the context of social life, culture, value systems of the environment and the goals of the individual himself, his capabilities and the degree of general arrangement, which has a relationship with psychosocial maladjustment.
3. The questionnaire *"The degree of satisfaction with one's own functioning in various areas" I. Karler, adapted by B. D. Karvasarsky* (2016), provided us with the opportunity to establish the sources of difficulties in four areas of the caregiver: married life, relationships with relatives, professional and social spheres [13]. This questionnaire was used to supplement and identify specific sources of difficulties in the functioning of caregivers in various spheres of their life, and also provided an opportunity to establish the targets of psychotherapeutic influence. Additionally, a specially designed structured questionnaire containing 26 questions was used [14-15].

Research results and discussion. Significant gender differences are observed, in particular, the vast majority of caregivers (94%) were women aged 25 to 63 who lived with the patient in the same house and were patients' daughters (33%), daughters-in-law (22%), granddaughters (21%), sisters (12%), remote relatives (8%) and neighbors (4%). Caregivers and their patients lived in the cities - 67.2%, in rural areas - 33.8%. The marital status of caretakers was the follows: first marriage - 48.6%, remarriage - 20.6%, civil marriage - 9.3%, single (divorced, widowed) - 21.5%. A significant part of the considered had secondary (31.9%) and specialized secondary (29.1%) education, higher and incomplete higher education - 15.5%, and 45.5%, respectively. Employed caregivers were 15.8%, had a part-time job (from 2 to 4 hours a day) - 35.6%, pensioners were 17.7%, unemployed - 30.9%.

On the basis of a detailed study and statistical analysis of the complaints of caregivers a general corpus of data of the identified functioning problems in various fields of activity was formed. The most important areas of maladjustment, which reflect the bulk of the identified dysfunctions, were identified. The main complaints of caregivers of patients with vascular dementia and Alzheimer's disease were feelings of grief and sorrow, despair and helplessness, shame of the patient's behavior, irritability and outbursts of anger, guilt, loneliness, exhaustion, fatigue, lack of time for themselves and other members. The feeling of grief and sorrow, despair and helplessness is a quite common psychological state of family members who learnt about a serious incurable illness of their closest relative and happened in 98% of cases. However, vascular dementia and Alzheimer's disease are experienced by the patient relatives much harder than their somatic pathology, since psychological contact with a loved one is gradually lost. The vast majority of relatives consider that the gradual destruction of the mental abilities of the patient cannot be helped in any way and you just need to come to terms with an unfortunate fate. The caregivers of such patients experience shame for the behavior of the patient, his anger, manifestations of the disease state (89%). Shame often literally haunts the relatives of patients, because they are hurt for their helplessness in the face of the disease, for the fact that sometimes negative feelings for the patient appear, they are embarrassed of others for his unacceptable actions and ashamed of the patient for their embarrassment. A similar situation develops because the caregivers of such patients feel lonely and subconsciously perceive the illness of a loved one as a punishment: “Why us?” Almost all (98%) relatives of patients with vascular dementia and Alzheimer's disease first experience inconvenience for the patient's behavior in front of other people. Caregivers also have a feeling of guilt (87%) towards the patient for the fact that it is difficult to care for them almost giving up their personal life, work, social contacts. Constant being with the patient makes a person a hostage to such a situation and lonely, because the patient is no longer a companion and other social contacts are lost. In 79% of cases caregivers of patients with vascular dementia and Alzheimer's disease

cease to maintain social contacts and avoid social life spending most of their time at home. Loneliness is especially acutely felt by socially active people who are forced to leave their favorite work and social activities in order to take care of a relative. Organizing family and social gatherings is also becoming a problem, as patients with vascular dementia and Alzheimer's disease do not tolerate the presence of large number of people. As dementia progresses, caregivers gradually assume responsibility for the patient's daily and financial responsibilities: paying utility bills, housekeeping, cooking, etc. Such an increase in the number of duties of the caregiver leads to constant stress and fatigue without assistance or the help of other family members. You can often hear the standard statements from caregivers: "I was torn between my family and my sick parents", "I don't know much about my parents' illness", "I can't cope on my own". The consequence of chronic fatigue, stress, disruption of the schedule of work and rest is the occurrence of symptoms of general exhaustion of the nervous system - irritability and bouts of anger. Irritation and anger arose predominantly among caregivers who had long-term self-care of patients with moderate and severe Alzheimer's disease. The emergence of these symptoms coincided with the stage of clinical manifestations of the disease (stage of moderate dementia).

As a result, six blocks of problems were identified. They correspond to the main areas of impaired psychosocial functioning: family, parental, professional, interpersonal, economic and property, informational. In most cases, there was a combination of several lesions of the listed components of adjustment. There were also situations when the defeat of one of the components according to the principle of the "domino effect" led to a violation of other areas of activity.

The methodology covers three main clusters of the caregivers' psychosocial functioning: macrosocial, which includes an assessment of socio-economic and informational and social maladjustment; mesosocial, including an assessment of professional and interpersonal maladjustment; and microsocial, including an assessment of family and parental maladjustment. These six areas cover the main areas of psychosocial adjustment (maladjustment) and made it possible to find violations of psychosocial functioning in all key areas.

Socio-economic maladjustment is a violation of the adjustment of an individual in a social environment under the influence of property, economic and financial factors. Informational and social maladjustment is a violation of the adjustment of an individual in a social environment under the influence of information factors. Professional maladjustment is a violation of the adjustment of an individual in a social (industrial) environment and the implementation of professional functions, associated with the influence of psychosocial factors. Interpersonal maladjustment is a violation of interpersonal interaction, microsocial relations and the formation of social bondings. Family maladjustment is a violation of family functioning and a violation of adjustment in the social environment under the influence of family relations. Parental maladjustment is a violation of the performance of parental functions and a violation of social functioning in connection with the performance of parental responsibilities. In addition to assessing each of the areas, an integral indicator of macrosocial, mezosocial and microsocial maladjustment was calculated. It was determined as the sum of indicators for the relevant areas, as well as an integral indicator of psychosocial maladjustment, which was determined as the sum of indicators for all areas of psychosocial functioning [16]. Based on the results of assessing the degree of psychosocial maladjustment the surveyed caregivers were divided into two groups.

The first group included 29 women, whose index did not exceed 19 points in any of the areas of psychosocial functioning, which corresponded to the absence of signs of maladjustment.

The second group numbered 74 caregivers, who had indicators of more than 20 points on at least one of the scales. It corresponded to the signs of maladjustment.

Among the caregivers without signs of psychosocial maladjustment were 11 people with psychogenic depression, 4 with adjustment disorder, 6 with anxiety-depressive disorder. An analysis of the features of psychosocial maladjustment in the studied contingent made it possible to obtain the following results.

Table 1

Mean values of psychosocial maladjustment degree on a scale for a comprehensive assessment of psychosocial maladjustment degree in different areas with and without signs of psychosocial maladjustment

Areas of psychosocial maladjustment of caregivers of patients with vascular dementia and Alzheimer's disease	*Mean values, M±m (points)*	
	with signs of maladjustment	*without signs of maladjustment*
Socio-economic maladjustment	10,48±2,77	23,69±8,56
Information and social maladjustment	11,38±2,71	23,59±8,55
Integral index of macrosocial maladjustment	21,86±5,40	47,28±17,10
Professional maladjustment	12,88±2,61	29,36±6,58
Interpersonal maladjustment	13,04±2,68	31,31±7,46
Integral index of mesosocial maladjustment	25,92±5,21	60,67±14,00
Family maladjustment	14,79±2,56	17,80±8,13
Parental maladjustment	14,27±3,13	16,24±8,06
Integral index of microsocial maladjustment	29,06±5,54	74,04±16,19
Integral index of psychosocial maladjustment	29,06±5,54	74,04±16,13

In the course of the work, the features of the quality of life (QoL) of caregivers of patients with vascular dementia and Alzheimer's disease with and without signs of psychosocial maladjustment were analyzed. Mean values in all areas of QoL and findings related to disagreements between them indicate a significant deterioration in the areas of socio-emotional support, social and service support, personal fulfillment and psychological (emotional) well-being.

In general, caregivers of patients with vascular dementia and Alzheimer's disease have two main trends: quality indexes are the highest in long-term caregivers (more than a year) and the period of care occurs at the stage of clinical manifestations of the disease (moderate dementia stages).

It was also found that caregivers of patients with vascular dementia and Alzheimer's disease with signs of psychosocial maladjustment have significantly worse quality of life indexes than caregivers without signs of psychosocial maladjustment.

The study of the degree of satisfaction with own functioning and the identification of sources of difficulties in various spheres of caregivers activities is shown in Table 2.

Table 2

The degree of satisfaction with their own performance in various spheres of the caregivers of patients with vascular dementia and Alzheimer's disease

Spheres of activity	Without signs of psychosocial maladjustment		With signs of psychosocial maladjustment	
	Абс.	% ± m	Абс.	% ± m
Family life	49	66,3% ± 4,8	47	68,1% ± 2,9
Relationships with relatives	52	70,9%± 2,5	48	69,5% ± 4,1
Professional sphere	36	53,5% ± 3,7	34	52,8% ± 3,3
Social sphere	28	58,1% ± 2,9	27	48,6% ± 4,7

According to the results of a study of caregivers of patients with vascular dementia and Alzheimer's disease, relationships with relatives (69,5% ± 4,1) and relationships in family (68,1% ± 2,9) life were the most widespread and severe dissatisfaction with their own performance. Also, noticeable difficulties prevailed in the following areas of performance: the professional sphere – 52,8% ± 3,3 and in the social sphere – 48,6% ± 4,7.

It must be noted that the difficulties in the performance in various spheres were observed equally in caregivers both with psychosocial maladjustment and without clinically defined psychosocial maladjustment.

Conclusions. Analysis of psychosocial maladjustment, quality of life and social performance of caregivers of patients with vascular dementia and Alzheimer's disease shows the need for specialized highly qualified medical and psychological assistance from specialized services that provide specialized outpatient care for patients with dementia and their families.

This makes it possible to identify and evaluate the key spheres of psychosocial maladjustment in caregivers of patients with vascular dementia and Alzheimer's disease.

The study underscores that the presence of psychosocial maladjustment plays a decisive role in the deterioration of the quality of life in caregivers of patients with vascular dementia and Alzheimer's disease while genesis of a neurotic disorder affects the quality of life but is of secondary importance.

A direct correlation was found between high points of the degree of dissatisfaction with one's own functioning in various areas with a high degree of severity of psychosocial maladjustment in caregivers of patients with vascular dementia and Alzheimer's disease. This facilitate the identifying the sources of performance difficulties that promote the disruption of general adaptive mechanisms.

The data obtained make it possible to influence the etiopathogenetic links in the formation of psychosocial maladaptive behavior and, accordingly, to improve the quality of diagnostic, therapeutic and preventive measures. These regularities should be taken into account when developing medical diagnostic and rehabilitation measures.

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ПСИХОСОЦИАЛЬНАЯ ДЕЗАДАПТАЦИЯ, КАЧЕСТВО ЖИЗНИ И СОЦИАЛЬНОЕ ФУНКЦИОНИРОВАНИЕ УХАЖИВАЮЩИХ ЛИЦ ПАЦИЕНТОВ С СОСУДИСТОЙ ДЕМЕНЦИЕЙ И БОЛЕЗНЬЮ АЛЬЦГЕЙМЕРА

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Резюме. Данная статья освещает вопросы изучения психосоциальной дезадаптации, качества жизни и социального функционирования ухаживающих лиц за пациентами с сосудистой деменцией и болезнью Альцгеймера. В исследовании принимали участие 103 человека, которые ухаживали за пациентами с болезнью Альцгеймера или сосудистой деменцией. Пациенты, получавшие помощь от ухаживающего лица, имели установленный диагноз по МКБ-10 F00-F01 и находились на диспансерном наблюдении у психиатра. На основании детального изучения и статистического анализа жалоб лиц, оказывающих уход за пациентами с сосудистой деменцией и болезнью Альцгеймера, сформирован общий «банк» выявленной проблематики функционирования в различных сферах их деятельности, а затем выделены основные наиболее важные направления дезадаптации, отражающие основную массу выявленных нарушений функционирования.

По результатам проведенного исследования выявлено, что решающую роль в ухудшении качества жизни лиц, оказывающих уход за пациентами с сосудистой деменцией и болезнью Альцгеймера, играет наличие психосоциальной дезадаптации, а неудовлетворенность собственным функционированием в различных областях опекунов выявляет ведущие источники трудностей.

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